Just a little needle stick

Pain and fear related to long-term needle injections in children with rheumatic diseases: An exploratory study

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Sammendrag

Barn med revmatiske sykdommer (RD) har de siste tiårene opplevd betydelig forbedring i symptombelastning og fysisk funksjon på grunn av medisinsk behandling som inkluderer metotreksat og biologiske legemidler. Behandlingen kan imidlertid kreve ukentlige subkutane injeksjoner fra måneder til år. I en tid med korte sykehusopphold får disse barna den første injeksjonen på sykehuset, og familien må deretter ta ansvar for den injeksjonsbaserte behandlingen hjemme. Nålerelatert smerte og frykt er vanlig hos barn, men til tross for økende forskning på dette feltet har det vært utfordrende å implementere evidensbaserte tiltak i klinisk praksis. Forskning på nålerelatert smerte og frykt hos barn med RD var begrenset ved oppstarten av denne studien. Imidlertid antydet noen få studier en sammenheng mellom smerte og medikamentrelaterte bivirkninger av metotreksat, samt problemer med å ta injeksjonene.

Hensikten med denne studien var å fremskaffe kunnskap om hvordan pasientopplæring for barn med RD og deres foreldre foregår, og hvordan smerte og frykt blir kommunisert og håndtert når barnet får sin første medisinske injeksjon. Videre var hensikten å utforske hvordan barn og foreldre ivaretar behandlingen med injeksjoner hjemme, samt hvordan sykepleiere oppfatter sine forutsetninger og kompetanse til å utføre pasientopplæring for disse familiene.

Denne studien har et utforskende kvalitativt design og inkluderer tre delstudier. Delstudie I består av videoobservasjoner etterfulgt av et kort intervju, fra ni opplæringsøkter i en barneavdeling. Det ble inkludert åtte barn (i alderen 5–15 år), elleve foreldre og syv sykepleiere. Delstudie II består av individuelle intervjuer med syv barn (i alderen 6–16 år) og åtte foreldre, samt fire fokusgrupper som inkluderte ni barn (i alderen 11–17 år) og åtte foreldre. Delstudie III inkluderte tre fokusgrupper med totalt fjorten sykepleiere som jobbet ved en barneavdeling og to poliklinikker.

Hovedfunnene i studien var at barn med RD, opplevde smerte og frykt i forbindelse med injeksjonene, men smertene var mindre intense enn de selv forventet. Frykten ble imidlertid ofte ikke satt ord på og ble ikke systematisk vurdert eller håndtert. Sykepleiernes kommunikasjonsform påvirket barnas følelsesmessige uttrykk. Bruken av en anerkjennende kommunikasjon så ut til å invitere barnet til å bli involvert i beslutningsprosessen om gjennomføringen av prosedyren. Funnene avdekket også kompleksiteten i opplæringsøktene og hvilke krav som stilles til sykepleiere for å håndtere både tekniske og følelsesmessige utfordringer samtidig.

Videre fremhever denne studien de mange utfordringene barn og foreldre opplever hjemme, på grunn av injeksjonsbehandlingen, alt fra tekniske til emosjonelle bekymringer. For å fullføre injeksjonene hjemme brukte familiene en rekke mestringsstrategier, dog med en potensiell risiko for å utsette barnet for bruk av fysisk tvang. Å skape rutiner og samarbeid så ut til å være en vesentlig ressurs for disse familiene. Det kommer fram i studien at barn med RD og deres familier trenger bedre oppfølging og veiledning, for å håndtere langvarig injeksjonsbasert behandling hjemme. Sykepleierne oppfattet sin pedagogiske rolle som betydningsfull, men pasientundervisningen for barna og foreldrene, forgår uten tilstrekkelige retningslinjer og organisasjonsstruktur, og overlater tilretteleggingen til hver enkelte sykepleiers individuelle kompetanse.

Denne studien bidrar med en dybdeforståelse og beskrivelse av nålerelatert smerte og frykt hos barn med RD under deres første medisinske subkutane injeksjon og videre i deres dagligliv med injeksjonsbasert behandling. Tolkningen av funnene i perspektivet til Peplau's mellommenneskelige teori, understreker viktigheten av barn-sykepleier-foreldre-relasjonen, både på sykehuset og hjemme. Relevante områder for fremtidig forskning inkluderer utvikling av sykepleieres kommunikasjonsferdigheter, forbedring av barns helsekompetanse, og implementering av nettbaserte løsninger som kanaler for informasjon og oppfølging av barn med RD.

Summary

In recent decades, children with rheumatic diseases (RDs) have experienced significant improvements in symptom burden and physical function due to medical treatments, such as methotrexate (MTX) and biological drugs. However, this treatment usually requires weekly subcutaneous injections for months and even years. In the era of short hospital stays, children with RDs receive the first medical injection at the hospital, and then the family must take responsibility for the injection-based treatment at home. Needle-related pain and fear in children are common, but despite increasing research in this field, it has been challenging to implement evidence-based measures in clinical practice. Research on needle-related pain and fear in children with RD was limited at the onset of this study. However, a few studies have suggested an association between pain and the drug-related side effects of MTX, as well as difficulty taking the injections.

The overall aim of this study was to contribute knowledge on how injection training for children with RDs and their parents takes place, and how pain and fear are communicated and managed when the child receives their first medical injection. Furthermore, the aim was to explore how children and parents take care of the treatment with injections at home, as well as how nurses perceive their own prerequisites and competence to perform patient education for these families.

The present study has an exploratory qualitative design and includes three sub-studies. Sub-study I consists of video observations followed by a short interview of nine training sessions at a pediatric ward and includes eight children (aged 5–15 years), eleven parents, and seven nurses. Sub-study II consists of individual interviews with seven children (aged 6–16 years) and eight parents, and four focus groups that included nine children (aged 11–17 years) and eight parents. Sub-study III included three focus groups with fourteen nurses working at one pediatric ward and two outpatient clinics.

The main findings of the study were that children with RDs experienced pain and fear related to needle injections, but the pain was less intense than they expected. The fear, however, often remained unspoken and was not systematically assessed or managed. The nurses’ type of communication influenced the children’s emotional expressions, and the use of acknowledging communication seemed to invite the child to become involved in the decision-making process of the training session. The findings also revealed the complexity of the training sessions and the requirements placed on nurses to manage both technical and emotional challenges simultaneously. Furthermore, this study highlights the many challenges children and parents experience when performing the injection treatment at home, which range from technical to emotional concerns. To complete the injections at home, the families used a number of coping strategies; however, with a possible risk of exposing the child to physical restraint. Creating routines and collaboration provided an essential resource for these families. The study findings showed that children with RDs and their families need better follow-up and guidance to manage long-term injection-based treatment at home. The nurses perceived their educational role as significant, but patient education for these children and parents takes place without sufficient guidelines and organizational structure and leaves the facilitation to the individual competence of each nurse.

This study contributes an in-depth understanding and description of needle-related pain and fear in children with RDs during their first medical subcutaneous injections and further into their daily lives with injection-based treatment. Interpreting the findings from the perspective of Peplau’s interpersonal theory emphasizes the importance of the child–parent–nurse relationship, both at hospital and at home. Relevant areas for future research include developing nurses’ communication skills, improving children’s health literacy, and implementing web-based solutions as channels for information and follow-up for children with RDs.

List of original articles

I Sørensen, K., Skirbekk, H., Kvarstein, G., Wøien, H. Children's fear of needle injections: a qualitative study of training sessions for children with rheumatic diseases before home administration, *Pediatric Rheumatology online*18 (2020) 13. https://doi.org/10.1186/s12969-020-0406-6

II Sørensen, K., Skirbekk, H., Kvarstein, G., Wøien, H. I don't want to think about it: a qualitative study of children (6–18 years) with rheumatic diseases and parents' experiences with regular needle injections at home, *Pediatric Rheumatology online* 19 (2021) 8. https://doi.org/10.1186/s12969-021-00495-4

III Sørensen, K., Skirbekk, H., Kvarstein, G., Wøien, H. Home administration of needle injections for children with rheumatic diseases: a qualitative study on nurses' perception of their educational role, *in review; Journal of Pediatric Nursing*
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Abbreviations

BURG	The Norwegian Rheumatism Association for Children and Adolescent (subgroup of the Norwegian League against Rheumatism)
CPG	Clinical Practical Guidelines
DMARDs	Disease modifying antirheumatic drugs
FPS-R	Faces Pain Scale revised
HPs	Health care professionals
IA	Interaction Analysis
IASP	the International Association for the Study of Pain
JIA	Juvenile Rheumatic Arthritis
NAKBUR	the Norwegian National Advisory Unit of Rheumatic Diseases in Children and Adolescents
MTX	Methotrexate
OUS	Oslo University Hospital
PE	Patient Education
PRINTO	the Peadiatric Rheumatology International Trials Organization
RDs	Rheumatic diseases
TA	Thematic Analysis
TLVlab	Teaching Learning Video lab at the Faculty of Educational Sciences
TSD	Services for sensitive data, University of Oslo
UNCRC	United Nations Convention on the Rights for the Child
VR-CoDES	Verona coding definitions of emotional sequences
WHO	World Health Organization

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1. Introduction

And then there's the needle injection…, every Sunday…, I dread and worry most of the week. I do not like the needle, and I hate the nausea!

These words came from a young girl attending an outpatient pain clinic due to chronic pain in addition to a rheumatic disease (RD). When I was talking to the girl about her experience of pain, I realized that no one had addressed her worries about the weekly subcutaneous injections. Her chronic pain condition was severe, but the weekly injections also significantly affected her quality of life, even though the medication was effective for arthritis.

Through my work as a pain clinic nurse and intensive care nurse, I have met many children who are afraid of needle-related pain. Some parents told about experiences where the child was physically held by healthcare providers (HPs) to complete a blood sample. Experienced pediatric nurses and psychologists confirmed that they often observed needle-related pain and fear among children with chronic conditions, even though they were used to hospitalization. Several nurses described difficulties in helping a child overcome procedural fears and admitted that they lacked competence in this area. They were also concerned about the management of subcutaneous injections at home because they were aware that some children with RDs had difficulty taking the medication after long-term treatment. These stories and experiences inspired me to think about whether the injections could have been introduced differently from the beginning to avoid entering vicious circles of pain and fear.

Pain in children has been an area of my professional interest for many years, and I was familiar with the huge amount of research on procedural pain and the existing evidence-based clinical guideline on reducing vaccination-related pain (Taddio et al., 2010). However, transferring knowledge into clinical practice is challenging, and the management of procedural pain and fear in children is an area where knowledge translation (KT) from research to clinical practice has so far been incomplete (Taddio & Rogers, 2015; Thrane et al., 2016). The last few decades have seen great improvements in disease control for children with RDs due to medical treatment with methotrexate (MTX) and biologics (Guzman et al., 2015).

However, until the onset of this study in 2017, we identified only three studies that had examined injection-related pain in children with RDs (Bechards et al., 2014; Mulligan et al., 2013; van der Meer et al., 2007). Children with RDs and their parents have to handle regular needle injections for a long time; however, in-depth knowledge about the introduction of and experiences with home-based injection treatment is lacking. Therefore, this study provides knowledge that is important to HPs caring for children with RDs to enable children and parents to administer long-term injection-based treatment at home. More precisely, in this study, we explore the pain and fear experienced during the child's first injection at the hospital, as well as the interactions between the child, nurse, and parents during the training session. Furthermore, we examine the experiences of children with RDs and their parents with long-term injection-based treatment at home, as well as the self-perceptions of nurses' competence in providing patient education.

1.1 Outline of the Thesis

After the introduction in Chapter 1, Chapter 2 provides a background with a brief overview of RDs in children and a historical overview of pain research in children. The literature review continues with an update upon study onset in 2017 on pain and fear related to needle injections and aspects of the child–parent–nurse relationship. The background section leads to the knowledge gaps and significance of this study. Chapter 3 presents the aims and research questions, and Chapter 4 outlines the central concepts and theoretical perspectives that have provided substance to the study. Chapter 5 provides a detailed description of the design and methods used in the three sub-studies, as well as an explanation of an updated literature search until December 2021. Chapter 6 summarizes the findings, and Chapter 7 discusses the main findings. Chapter 8 presents the methodological considerations. The thesis ends with the conclusion of this thesis, along with implications for clinical practice and recommendations for further research.

2. Background

This chapter presents a brief introduction to the patient group, children with RDs, followed by a historical overview of the developments in research and attitudes toward pediatric pain. Furthermore, I present research relevant to procedure-related pain and fear, and elaborate on the child–parent–nurse relationship. Finally, I summarize the rationale for this study.

2.1 Children with Rheumatic Diseases

Juvenile idiopathic arthritis (JIA) is a heterogeneous disease with arthritis in children (< 16 years) that lasts for at least six weeks (Prakken et al., 2011; Ravelli & Martini, 2007). It is the most common inflammatory RD in childhood and may lead to severe disability. The International League of Associations for Rheumatology (ILAR) has categorized JIA as Systemic arthritis, Oligoarthritis, Rheumatoid-factor-positive polyarthritis, Rheumatoid-factor-negative polyarthritis, Enthesitis-related arthritis, Psoriatic arthritis, and undifferentiated arthritis (Guzman et al., 2015; Ravelli & Martini, 2007). The prevalence of JIA in published reports varies from 16–150 per 100,000 (Prakken et al., 2011), with a pooled estimated prevalence of 32.6 per 100,000 (Thierry et al., 2014). In the Nordic countries, the annual incidence is approximately 15 per 100,000 children (Berntson et al., 2003; Riise et al., 2008). The average age of disease onset is between five and nine years, with a peak incidence in preschool-aged children and adolescents (Guzman et al., 2015; Nordal et al., 2011; Ravelli & Martini, 2007).

The introduction of disease-modifying antirheumatic drugs over the last two (to three) decades has improved the overall outcomes for children with JIA (Guzman et al., 2015; Vanoni et al., 2017). For some of these children, however, the risk of relapse or maintenance of the active disease is unpredictable, and the need for medication will continue into adulthood (Selvaag et al., 2016). Advances in medical treatment for many of these children will involve the administration of regular subcutaneous injections. As some children with Behçet's disease and juvenile dermatomyositis are also offered injection-based treatment, we use the umbrella term Rheumatic Diseases (RDs) in this study.

2.2 Historical Perspectives on Pain Research in Children

Surgery on infants was routinely performed without adequate anesthesia until the 1980s (Rodkey & Pillai Riddell, 2013). There was a common understanding that newborns, especially premature babies, could not feel pain and that they did not tolerate anesthesia. Therefore, surgery could safely be accomplished with only oxygen and a paralytic drug. Babies' responses to nociceptive stimuli were explained as reflex reactions, and research was used to argue for such a view. Darwin had used infant behaviors as evidence of hereditary traits or reflexes, which, like the emotional expressions of animals, savages, and lunatics, were considered reflexive actions, based on habit and were unreliable pain markers. Scientists in the 19th century conducted experiments on infants with pinpricks and concluded that pain was poorly developed in neonates, since the babies did not give evidence of discomfort. Increasing wetness in the eyes was not considered related to the pinprick. The experiments on infants continued into the first half of the 20th century, when scientists were influenced by a reductionist behaviorist perspective, searching for reflexes rather than consciousness. Such a preconception led to an interpretation of the results supporting the previous evidence about *the decorticate infant*, contributing to continued experimentation on infants without any ethical consideration (Rodkey & Pillai Riddell, 2013).

However, the German pediatrician Albrecht Peiper published results in the 1920s that showed a clear reaction of movement and screaming during needle prick on the heel, although premature babies had slower response times. He also emphasized individual differences and was concerned with the ethical implications of his findings. He stated that newborns' and infants' sensitivity to pain implies their having the same right to protection as adults, but are defenseless when their rights are violated. Peiper's warnings and ethical challenges were largely ignored by scientists, and the skepticism of infant pain among medical authorities justified the withholding of anesthesia from infants (Rodkey & Pillai Riddell, 2013). One example is Swaffords and Allan, who in 1968 concluded that children seldom need medication for pain relief after surgery, as they tolerate discomfort well. They reported that only 26 of 180 patients in their pediatric intensive care unit needed narcotics after surgery, and they justified this claim by comparing the response and cortical activity of the baby to that of a patient receiving thiopental anesthesia, which meant they could perhaps feel some pain, but not remember (Swaffords & Allan, 1968). They further discussed the positive effect of preoperative preparation by play, and the importance of relieving children's anxiety by allowing the parents to be present throughout the induction of anesthesia. Swaffords and Allan (1968) were also concerned about drug addiction and respiratory depression and concluded that children under 10 years seldom require narcotics; they recommended using suggestions and distractions rather than analgesics to manage children's complaints.

Ethical concerns were not open to questioning until the 1980s, motivated by humanitarian concerns. In 1974, the Declaration of Helsinki stated that research should only take place in connection with necessary medical procedures (Rodkey & Pillai Riddell, 2013). However, the under prescription of analgesics continued beyond the 1980s, despite most pediatric anesthetists believed that neonates could feel pain. They considered objective signs of pain potentially misleading, and were reluctant to prescribe analgesia (Purcell-Jones et al., 1988). Jeffery Lawson was a premature baby who, in 1985, underwent extensive surgery without adequate analgesia and later died. His mother, Jill, provided public awareness on the topic and contributed to improvements in pain research and treatment for children, and by 1995, 91% of anesthetists had provided opioid analgesia to infants for major surgery (de Lima et al., 1996).

Pain research and views of children have developed substantially over the last 40 years, from regarding infant's response to painful stimuli as reflexes until today, when children receive more adequate and individual pain treatment. However, recent studies continue to show that children still experience pain related to medical procedures and treatment (Birnie, Chambers, et al., 2014; Shomaker et al., 2015; Thrane et al., 2016) and that available pain management strategies are not fully utilized (McMurtry et al., 2015; Twycross, 2010).

2.3 Pain and Fear Related to Needle Injections in Children

In 1979, the International Association for the Study of Pain (IASP) defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Bogduk, 1994).

The definition took into account that pain is a subjective experience and included both the sensory and emotional dimensions of pain; however, the definition has been criticized for the reliance upon a person's ability to *describe* the experience to qualify as pain (Anand & Craig, 1996). This meant that, for example, small children, intensive care patients, and older people with dementia were excluded. Pain cannot be understood as nociception only, but as a phenomenon influenced by life experiences and learned experiences (Twycross & Williams, 2014), and the biopsychosocial model has been important to understand and explain pain holistically (Engel, 1977). It is important to recognize procedural pain from a biopsychosocial perspective to understand why a child's anxiety and fear of pain are often more significant for the total experience than the nociception from the needle stick (Ayers et al., 2011).

2.3.1 Needle- and injection-related pain and fear

Needles are used routinely for the treatment and prevention of diseases, beginning in early life with several vaccinations. The development and administration of vaccines form one of the greatest health advances in the general population in the 20th century, preventing several dangerous diseases, and they are the most experienced needle procedure for people worldwide (McMurtry et al., 2016). The number of vaccines and combinations varies throughout history, but most are administered during childhood by needle injections. According to the Norwegian Institute of Public Health (NIPH), Norwegian children are usually offered 18 vaccinations (before the coronavirus vaccination started) that require needle injection before they are 15 years old (Stålcrantz, 2008).

Children with chronic diseases, such as type 1 diabetes, immune deficiency, cancer, and rheumatism, are increasingly offered treatment requiring regular needle injections in addition to various needle procedures performed at the hospital (e.g., intravenous cannulation, blood tests, lumbar punctures, and joint injections). Pain related to needle procedures is common, and both children and adults report a fear of needles (Taddio et al., 2012). Many children and adults manage their needle procedures very well, but others develop anxiety and fear that affects future responses to healthcare services (McMurtry et al., 2016). Not only the child receiving the injection, but also the families and HPs who must administer the injections are often anxious and distressed during these procedures (Schechter et al., 2007). Experiences of painful needle procedures during childhood may contribute to long-lasting changes in physiological and behavioral responses (Fitzgerald & Walker, 2009). Research in neuropsychology suggests that early pain stimulation, especially in infants, may lead to hypersensitivity of the peripheral and central nervous systems (Fitzgerald & Walker, 2009), which may cause increased pain in later procedures (Walker et al., 2016). A Norwegian study showed that adolescents who were born preterm and had been exposed to painful stimuli as neonates withdrew from the standardized coldpressor task (hand in ice water) earlier than a control group of adolescents born at term (Vederhus et al., 2012). However, their pain scores were similar to those of the controls. Painful procedures can create fearful memories among healthy children, leading to anticipatory fear and increased pain in future procedures (Noel et al., 2012). These studies suggest that memories of pain can be a factor in the transition from acute to persistent pain that develops through operant learning processes, as well as altered processing in the nervous system, and illustrate the complexity of the development of pain.

Inadequate pain control has been associated with high levels of distress and anxiety (Blount et al., 2006; Diseth, 2006). Anticipatory distress and fear of needles seem to heighten pain experiences and anxiety reactions to medical procedures (McMurtry et al., 2015; Racine et al., 2016), and may even lead to fear of HPs (Gullone, 2000). According to Gullone (2000), fear is a normal reaction to a real or imagined threat with a primary function of promoting survival, and is adaptive to development. The prevalence and intensity of normal fear tend to decrease with increasing age, and specific fears are often temporary. Fear in infants relates to immediate, concrete, and distinct stimuli, which are largely noncognitive, while fears later in childhood and adolescence relate to anticipatory, abstract, and more global stimuli and events (Gullone, 2000). Needle-related distress can be viewed as a continuum ranging from needle fear to more severe needle phobia. McMurtry et al. (2015) reviewed the different degrees as follows: Fear is an alarm reaction to an immediate threat (real or perceived), and anxiety is a negative emotional state characterized by the anticipation of a future threat. Phobia has specific diagnostic criteria in which children express obvious discomfort by crying, clinging, or showing anger, and the reaction is not in proportion to the danger. Another term often used in the research literature is *distress*, which is used to describe an unpleasant or negative expression, often associated with pain, anxiety, or sadness, or as a combination of several (McMurtry et al., 2015). The terms *fear* and *anxiety* are often used interchangeably in the pediatric pain literature.

The development of needle fear commonly occurs in early to middle childhood and most often between the ages of 5 and 10 years (McMurtry et al., 2015; Taddio et al., 2012), which is about the same age as the onset of pediatric RDs (Guzman et al., 2015). Needle fear and phobia may follow into adulthood and cause denial of health care, including blood tests, vaccinations, and dental treatments at all ages (McMurtry et al., 2015; Taddio et al., 2012). Although fear of needles is common among children, it is often challenging for HPs to manage (Taddio et al., 2012). Despite the research and increased knowledge of the last few decades, children are still being held by force to complete procedures (Bray et al., 2015; Svendsen & Bjørk, 2014). Physical restraint is even more evident when procedures are perceived as urgent or when the child is younger (Bray et al., 2015). The long-term consequences of repeated traumatic procedures in childhood may be severe, and particularly harmful when being performed regularly by the parents over a long time (Diseth, 2006). Threatening events seem to have a formative force in the brain, as survival requires that people remember dangers to which they have been subjected (Nordanger & Braarud, 2014). When activation is tolerable, however, the child can maintain a sense of control, and the experience is integrated as acceptable for the child.

Research on injection-related pain and fear in children with chronic diseases who need injection treatment for years has so far been limited compared to children receiving a limited number of injections. However, injection-related fear is common in children with type 1 diabetes, although it declines with increased age and duration of treatment (Cemeroglu et al., 2015; Howe et al., 2011). Fear of insulin and injections is associated with poor glycemic control, which may cause severe psychological and physiological complications, as well as an increased risk of mortality (Fu et al., 2009). Thus, it is important to identify children with a high degree of needle fear to improve glycemic control. At the onset of the present study, injection-related pain and distress in children with RDs receiving MTX had shown mild pain, however, with increased inconvenience due to common side effects including nausea, vomiting, or anticipatory nausea (Bechard et al., 2014; Mulligan et al., 2013; van der Meer et al., 2007). Two of these studies were proxy reports from parents (Mulligan et al., 2013; van der Meer et al., 2007). Mothers reported that over 50% of the children had experienced either one or more of the following reactions: fear of injections, fear of blood tests, nausea or vomiting, or anticipatory nausea (Mulligan et al., 2013). Bechard et al., (2014), also included children's self-reports of pain and concluded that subcutaneous injections with MTX caused mild pain intensity; however, 61% of the children experienced side effects that was associated with increased pain (Bechard et al., 2014).

2.3.2 Strategies to manage children’s injection-related pain and fear

Among children with JIA, the strategies most commonly used to cope with pain and distress are ice (34%), comfort positions (51%), rewards (49%), reassurance (54%), and distraction (51%), and analgesic medications (22%) (Bechard et al., 2014). Several systematic reviews have published evidence-based recommendations for nonpharmacological and pharmacological strategies to manage pain and needle fear (Birnie, Noel, et al., 2014; Chambers et al., 2009; Harrison et al., 2014; Pillai Riddell et al., 2015; Schechter et al., 2007; Uman et al., 2013). Managing pain and needle fears can be explained as assisting the child in coping with sensory and emotional stress due to the actual pain and the fear of pain. Thus, many researchers recommend treating needle-related pain with psychological, pharmacological, and combined interventions (Blount et al., 2006; Flowers & Birnie, 2015).

Nonpharmacological strategies

Psychological interventions include preparation by playing, learning, rehearsing, and integrating coping strategies that may increase self-efficacy and provide the child with predictability and control (Flowers & Birnie, 2015). Developmental and age-appropriate approaches are important in the assessment and treatment of all types of pediatric pain (Thrane et al., 2016). Preparation prior to procedures includes providing sensory and procedural information, as well as training in coping skills (Cohen, 2008). Pre-procedural preparation through play (e.g., using teddy bears for demonstration and training) has been shown to reduce needle pain and be helpful in learning coping strategies (Dalley & McMurtry, 2016).

Distraction is a nonpharmacological measure widely investigated and recommended for reducing procedural pain (Birnie, Chambers, et al., 2014; Cohen, 2008; Koller & Goldman, 2012; Taddio et al., 2010; Thrane et al., 2016). There are several easy-to-use techniques aimed at removing a person’s attention from the procedure. However, the chosen technique must be adapted to the child’s age, temperament, and interests (Koller & Goldman, 2012; Schechter et al., 2007; Thrane et al., 2016). Examples of measures that may be appropriate and work for children < 3 years include using a rattle, singing, or blowing bubbles, and for school-aged children include counting, talking about something else (the family pet), and watching a video. Recommendations for teenagers include talking about upcoming holidays, telling jokes, or watching a video. More innovative devices, such as the Buzzy, which adds coldness and vibration near the injection site (Moadad et al., 2015), and virtual reality (Hua et al., 2015), have been shown to be effective for older children. Although computer tablets (e.g., iPads, iPods, and smartphones) are popular among children and easy to use, a current randomized controlled study did not show their effectiveness for distraction during vaccinations (Burns-Nader et al., 2015). Child-led distractions, such as listening to music, watching a video, playing a videogame, playing with a toy, or reading an age-appropriate book, are shown to be effective (Taddio et al., 2010). The child is involved in the selection of a distraction strategy, and the activity is performed without any direction from another person. Nurse-led distraction is also found to be effective and can be used with children of all ages (Chambers et al., 2009; Taddio et al., 2010). Parent-led distraction may also be effective, but inadequate training or parents being too distressed leaves a risk that such coaching may fail. Parents need education about distractions and behaviors that promote the child's ability to cope before the onset of the procedure (Taddio et al., 2010).

Breathing techniques have been shown to be effective in reducing children's self-reported pain and nurses' reported distress (Chambers et al., 2009). Slow deep breathing is easy to use and may serve as a relaxation strategy and distraction (Taddio et al., 2010). Many hospitals have implemented medical clowning (Meiri et al., 2016), music therapy (Nguyen et al., 2010), and play specialists (Li et al., 2016). These resources have been shown to reduce procedural anxiety and negative emotions in hospitalized children.

Pharmacological strategies

Different drugs can be considered for procedural pain and fear; however, medications must be used with caution and in the right setting. Sweet tasting solutions have been shown to be effective for procedural pain in neonates and children up until one year and should be regarded as a pharmacological intervention (Harrison et al., 2015). However, sweets are not shown to be effective for children older than one year. Topical anesthetics (e.g., EMLA) are easy to apply and significantly reduce needle-related pain, but not necessarily the fear (Cordoni & Cordoni, 2001; Taddio et al., 2010). A well-known, safe, and effective analgesic that reduces pain and fear of needles is nitrous oxide (Baskett, 1994), which is recommended as a first choice alternative when a drug is needed during painful minor procedures (Pedersen et al., 2013). The effect of medication usually administrated for acute and postoperative pain seems to have a limited effect on procedural pain. A Swedish research group conducted RCT studies on children 1–18 years with cancer during the insertion of subcutaneous needle ports and showed that neither paracetamol (40 mg/kg) nor morphine (0,25 mg/kg) administered orally had any effect on pain, fear, and distress (Heden et al., 2011, 2014). Children's anxiety and fear of needles are recognized, and midazolam has been a popular and very much used drug before medical procedures. Midazolam does not provide analgesia, but may have an effect on reducing fear and distress in children < 7 years before needle procedures (Hedén et al., 2009). Dexmedetomidine is increasingly used in children due to its sedative, anxiolytic, and mild analgesic properties, with no depressant effect on respiratory drive (Mahajan & Dash, 2014), and may be administrated intranasal without any intravenous access.

2.4 Aspects of the Child–Parent–Nurse Relationship

A child's response to pain is individual and influenced by learning and the environment, as well as genetic factors (Young, 2005). Several aspects together create each child's individual pre-procedural pain beliefs, attitudes, and coping skills. The interaction with parents and nurses, the characteristics of a procedure and environment, and the use of specific strategies to reduce pain and fear further shape the child's response to pain. Factors that can influence the experience of pain and fear are pain coping style; familiar role models; social learning from peers, media, and authority persons; perceived secondary gains; and medical fears (Young, 2005). Determinants that cannot be changed include age, developmental stage, gender, ethnicity, and temperament, which means that the nurse must have sufficient knowledge to meet each child's individual needs.

2.4.1 Children's rights and perceptions of medical procedures

The United Nations Convention on the Rights for the Child (UNCRC) has clearly stated that every child has a right to self-determination, dignity, respect, non-interference, and the right to make informed decisions (United Nations Human Rights, 1989). Article 17 of the UNCRC emphasizes that children have the right to get information in a language they understand, which means that information needs to be age-appropriate and adjusted to each child's developmental stage. Pre-procedural preparation and information have proven effective and can reduce children's pain and fear of needles in different contexts (Kajikawa et al., 2014;

Uman et al., 2013; Schechter et al., 2007). Involving children in decision-making, getting access to information, and having contact with a nurse may have a positive influence on children's experiences (Bray et al., 2012), while negative experiences may lead to reluctance toward later medical procedures (Duff et al., 2012). Adherence to long-term treatment has been shown to be challenging for adolescents with chronic conditions. Important barriers include relations with parents and peers, forgetting to take medication, physical impairment, and the absence of perceived health benefits, as well as side effects and administration problems (Hanghøj & Boisen, 2014). Therefore, clinicians have to acknowledge adolescent's perspectives to provide treatment responsibilities and self-management.

Despite the UNCRC being one of the most ratified human rights, children have still not been sufficiently involved in decision-making regarding their healthcare (Coyne, 2008). According to Article 19 of the UNCRC, children have the right to be protected from violence. Children may be reluctant to cooperate during medical procedures, while HPs and parents will perform the procedure as quickly as possible and use holding. Holding is described by several terms: clinical holding, therapeutic holding, restrictive intervention, physical restraint, and supportive holding; however, these terms have different meanings. Restraint means that adults hold children by force against their wishes, while clinical holding indicates children's acceptance of receiving a supportive hold (Bray et al., 2016). Physical restraint may be traumatic for the child, parents, and HPs who are responsible for the procedure. Adults describe children's reluctance as an expected obstacle that must be overcome, rather than as a cue to use a different approach (Bray et al., 2016). Furthermore, the HP's attitude toward using physical restraint is often justified by the argument that the procedure is done in the interests of the child. The difference between *a child perspective* and *the child's perspective* is not always distinguished in the literature. A child perspective is characterized by the adult's perception of children's experiences and actions with the child's best interests, while the child's perspective is characterized by the child's own experiences and perceptions of their lives and actions (Nilsson et al., 2015; Söderbäck et al., 2011). In research, these perspectives may provide sufficient knowledge depending on the aim of the research; however, in clinical practice, the child's perspective should be respected whenever possible. Procedures are often carried out without taking the child's cues seriously. There is usually a window of opportunity in the beginning of a procedure where the child is calm, and where it is possible to initiate and maintain child-centered engagement, nonpharmacological measures, and co-operation (Bray et al., 2016; Svendsen & Bjørk, 2014). Medical conditions entailing ongoing procedural pain and distress for the child may cause long-lasting psychological problems, even if the procedure is performed in the best interests of the child (De Young et al., 2012; Diseth, 2006). Traditionally, children's experiences and perceptions have been less visible in research than adults' opinions of children's perspectives (Bray et al., 2015). However, children's perspectives may differ from parents' reports and may contribute to a different understanding of children's needs and experiences (Söderbäck et al., 2011). Considering that adult HPs still use holding and restraint to complete medical procedures (Cummings, 2015; Svendsen et al., 2015) indicates that the right given by Article 19 in the UNCRC has not been sufficiently implemented in clinical practice.

2.4.2 Parents' perspectives and roles

As parents know their child, they are usually able to interpret the child's signals of pain and fear, but they are not necessarily able to help their child cope with the distress. Supporting parents in managing their own anxiety about injections will make them better prepared to support their children (Bauchner et al., 1994; De Young et al., 2012). The interactions between children, parents, and HPs during medical procedures are complex and depend on several factors. Studies have shown an association between adult behavior and child distress (Blount et al., 1989; Chambers et al., 2009). Parents' (and nurses') communication that relies on reassurance, intimidation, and criticism is more likely to increase children's fear than soothe them. Reassurance, such as "it will be over soon" or "it won't hurt," is often a type of communication used by both parents and nurses (Blount et al., 1989; Taddio et al., 2015). However, the effect of reassuring communication depends on whether the child is in a relaxed state, as well as the adult's facial expressions and vocal tones, but it is commonly shown to be ineffective in reducing pain and is thus advised against (McMurtry et al., 2010; Taddio et al., 2010). Nonprocedural talks, humor, coaching to use distraction, and deep breathing are associated with children's coping behavior (Blount et al., 1989; Chambers et al., 2009). A study of parents of children with JIA showed that the most commonly used coping strategies to comfort the child before injections were reassurance, distraction, and rewards (Bechard et al., 2014). Rather than telling a child that a procedure "won't hurt," researchers recommend inviting children to express their own experiences of pain and fear by using age-appropriate tools like the Faces Pain Scale–Revised (FPS-R) (McMurtry et al., 2011; Thrane et al., 2016).

According to Bandura’s (1991) theory of social learning, children may learn anxiety and avoidance behavior from their parents’ expression of anxious thoughts and behavior in front of the child. However, the relationship between parents and children’s behavior during a medical procedure is likely bidirectional in nature (Blount et al., 1989). Parental behavior is a strong predictor of pain-related distress and fear in children during medical procedures, and a child’s distress leads to parents’ distressful behavior (Blount et al., 1989; Racine et al., 2016). It seems that the parents’ behavior tends to take precedence over the child’s coping response, and coping promoting behavior often leads to the child’s coping behaviors (Campbell et al., 2017). Medical procedures are also distressing for parents, and there is a risk that parents attend the role of helping the nurse get the procedure done instead of supporting their child (Bauchner et al., 1994; Svendsen et al., 2015), which may lead to the use of physical restraint to complete a procedure (Diseth, 2006; Svendsen et al., 2015). Witnessing their child in pain can cause similar psychological distress to their child as injuries and medical care, and positive associations were found between a child’s and parent’s posttraumatic stress symptoms (De Young et al., 2014). To be an emotional resource for their child during a painful procedure, rather than assisting the nurse, parents need to receive preparation and information about their supporting role (Bauchner et al., 1994). Reducing children’s pain and fear during medical procedures tends to improve both parents’ and children’s long-term psychological well-being (De Young et al., 2014). Parents’ behaviors and responses to a child play a central role in the child’s progress and maintenance of pain expressions. Parents of children with JIA experience a complex emotional journey from the onset of the disease and the diagnosis, with anxiety, shock, and confusion to hope and gratitude, as well as fatigue and frustration from the ongoing treatment and fear of flare-ups (Gómez-Ramírez et al., 2016). These emotional journeys will probably influence their support for their child during needle injections at home.

2.4.3 Nurses’ responsibilities and roles

Nurses have a professional, ethical, legal, and personal responsibility for their actions and deliberations in their nursing, with the aim of promoting health, preventing disease, restoring health, and alleviating suffering (International Council of Nurses, 1953). The nurse’s ability to administer needle injections to a child while providing patient education is a complex nursing task that requires the nurse to consider all of these areas of responsibility.

It is recommended that nurses use evidence-based knowledge to implement painful procedures (Duff et al., 2012; Schechter et al., 2007). Clinical Practical Guidelines (CPG) for acute procedural pain have been developed (Lee et al., 2014; Taddio et al., 2010); however, implementation in clinical practice has not been completed (Taddio & Rogers, 2015). The reasons could be several, but a Canadian multidisciplinary team, Help Eliminate Pain in Kids (HELPinKIDS), has pointed out important factors to include the effectiveness of different strategies and available resources, as well as the cooperation and adaptation to barriers (Taddio et al., 2015). The HELPinKIDS team advised guideline developers to plan KT from the onset of the development of a guideline. When this study started, there were no national clinical guidelines for procedural pain in Norway. The CPG has highlighted the importance of using an appropriate injection technique, coping strategy, and body position of the child to reduce pain during injections (Taddio et al., 2015). Furthermore, qualitative studies have pointed out that establishing a relationship with the child (Svendsen & Bjørk, 2014) and communicating in a language that the child understands (Karlsson et al., 2014) are important factors if the use of nonpharmacological approaches should be effective. Engaging in "small talk" may be just as important as providing basic information, and encouraging parents to support the child and to use positive coping promoting strategies during procedures is significant (Karlsson et al., 2014). The interaction between the nurse, child, and parents during needle procedures is complex and has been less investigated than the use of specific coping strategies. One of the nurses' ethical duties is to act as the patient's advocate (MacDonald, 2007), which means that whenever possible, the nurse should respect the child's and parents' perspectives and opinions (Nilsson et al., 2015). Nurses should protect a child from being held against their will to complete a medical injection (United Nations Human Rights, 1989). However, in situations where the nurses fail to impede such a negative experience for the child, it is necessary to reflect upon how such a demanding procedure will bring additional negative emotions, e.g., guilt, for the nurse as well. Nurses' ability to balance diverse needs and to preserve dignity for all involved in the procedure will often be the key to the quality of care (Karlsson et al., 2014; MacDonald, 2007).

2.5 Summary and Knowledge Gaps

Research in recent years has increased knowledge about pain and fear in children during medical procedures. To date, most research has focused on pain during procedures performed by HPs a limited number of times in a child's life, such as vaccinations or peripheral vein punctures. Due to the modern treatment of pediatric RDs, many children can look forward to an easier future than before regarding the symptom burden. However, research on these children's experiences of needle-related pain and fear was limited at the onset of this study. Short-term hospitalization entails the overriding goal that children with RDs and their families should take care of injection-based treatment at home. However, how these training sessions take place and the needs of the families who manage the injections at home have not been sufficiently investigated. Furthermore, knowledge of the child–parent–nurse interaction during the training session and their management of children's pain and fear, both at the hospital and in the families' daily lives, was lacking. How the nurses perceived their educational role, pedagogical competence, and practice in the training sessions was also not described in previous literature.

3. Aims and Research Questions

The overall aim of the study was to provide new knowledge on how injection training for children with RDs and their parents takes place and how pain and fear are communicated and managed during the first medical injection. Furthermore, the aim was to reveal what would help children and parents better take care of injections at home, and what prerequisites and competence nurses need to perform the training sessions. The following sections describe the specific aims and research questions for each sub-study.

3.1 Sub-Study I

Needle-related pain and fear represent a risk for children with RDs to refuse long-term injection-based treatment. The nurse's management of pain and fear during the first injection and the patient education provided may affect the patients' later experiences and the injection treatment at home. The child–parent–nurse interaction and communication may also affect the child's emotional expressions. Therefore, the aim of sub-study I was to (1) explore children's expressions of pain and fear during training sessions for the home administration of subcutaneous injections, and (2) examine how nurses' and parents' communication affected children's expressed emotions.

3.2 Sub-Study II

Long-term treatment with needle injections may be a considerable stress factor for children with RDs. How children and parents experience injection-based treatment and handle pain and fear at home has not been fully explored. Thus, sub-study II aimed to explore how regular needle injections affect children with RDs and their parents in their daily lives. The research questions were as follows:

- *How do children and parents experience long-term needle injections administered at home?*
- *What characterizes children's and parents' use of coping strategies at home?*

3.3 Sub-Study III

Managing injection-based treatment at home for children with RDs and their families requires patient education. However, nurses' competence and prerequisites to provide patient education and to accommodate the emotional needs of children and parents have not been sufficiently described. Therefore, the aim of sub-study III was to explore nurses' perceptions of their educational role, pedagogical competence, and practice in teaching children with RDs and their parents to manage subcutaneous injections at home.

4. Central Concepts and Theoretical Perspectives

This exploratory qualitative study has an inductive approach. The theoretical perspectives and concepts were not predetermined; however, they emerged along with the development of the study, illuminating and actualizing the results.

4.1 Coping

Coping is a commonly used term that may be understood in several ways. The term needs elaboration because children's *coping* is often considered a goal during needle injections. Coping includes an experience of cognitive, emotional, and instrumental control, which means control over one's thoughts, emotions, and practical skills (Havik, 1989). This basic experience may reflect a person's self-esteem and self-confidence. Control over a person's thoughts is strengthened when the situation becomes recognizable and understandable, which means that children need information that they can understand. *Emotional control* may reflect what a person thinks about themselves based on their assumptions (Havik, 1989). This applies to the child, parent, and nurse in a training session and is an expression of the person's self-esteem. *Instrumental control* is about mastering the tools and skills required in the situation, e.g., handling the equipment and administering needle injections (Havik, 1989). Psychological coping mechanisms are commonly termed as *coping strategies* or *coping skills*. The term coping generally refers to adaptive (constructive) coping strategies, which are strategies for reducing stress. Other coping strategies may be inappropriate if they increase stress.

Increased confidence in coping strategies has been shown to reduce pain and distress in the context of procedural pain (Chen et al., 2000). A person may have high self-esteem in general, but this becomes insufficient when confronted with new situations. Self-efficacy affects the choices and effort a person puts into a new task and endurance when facing difficulties and setbacks (Bandura, 1997). However, self-efficacy may be changed by gaining new knowledge and skills, and by having a desire for positive results. Prior experiences of success will make a person believe that they can apply this success to the current situation (Bandura, 1997).

Coping is affected by the difficulty of the task and the effort required to achieve the goal, and is closely related to the assessment of threats, stress, and emotions (Lazarus, 2006). Children's pain coping has been conceptualized by measuring distress or lack thereof as an indicator of coping (Taylor et al., 2011). However, stress alone does not account for a person's well-being, but effective coping will keep the stress under control (Lazarus, 2006). Coping responses may be viewed as deliberated physical or mental actions as a response to a perceived stressor (e.g., distraction, deep breathing), while coping outcomes are the explicit consequences of the coping responses (e.g., crying or screaming). When a child cries during a medical procedure, it is not just a symptom of distress or pain; it may be a natural coping response (Taylor et al., 2011). Coping is also viewed as a relational process in which the individual participates in a dynamic, mutually influential relationship (Lazarus, 2006).

4.2 Communication

Communication is a core concept in patient supervision and is significant in the interaction between nurses and patients in patient education (Tveiten & Severinsson, 2006). Communication includes both information and behavior, and the relationship between the nurse, parent, and child affect the content and function as "metacommunication" (Tates & Meeuwesen, 2001). Children's rights to express their opinions and receive information have long been established (United Nations Human Rights, 1989), and Gene Stanford (1991), addressed the importance of strong communication skills during children's painful procedures, when some of his current colleagues still doubted the existence of children's pain. Much of Stanford's (1991) advice has similarities with evidence-based pain management measures for children (described in Section 2.3.2). The development of a patient-centered approach has led to a shift in the doctor–patient relationship from extremely asymmetrical to more equal, but children have been largely overlooked as active participants in *doctor–parent–child* communication (Tates & Meeuwesen, 2001). Many aspects play a role in the communication between the HP, child, and parent. Tates and Meeuwesen (2001) highlighted the relational aspects, the structural aspects, and the content of the interaction. The relational aspects include the cognitive need to be informed (the need to know and understand) and the emotional need to be taken seriously (the need to feel known and understood). As opposed to a strict biomedical approach to medicine, biopsychosocial and patient-centered models in healthcare encounters recognize the importance of emotions. Emotional concerns may be presented as *cues* and *concerns*, where concerns are defined as an "explicit and clear verbalization of an unpleasant emotional state, and cues are verbal or non-verbal hint to an underlying unpleasant emotion" (Zimmermann et al., 2011). The coding system "The Verona

Coding Definitions of Emotional Sequences” (VR-CoDES) has enabled in-depth studies of patients’ expressions of emotional distress in communication with HPs (Piccolo et al., 2017; Zimmermann et al., 2011). HPs’ responses to cues and concerns may open up for emotional talk and contribute to improved emotional regulation by the patient (Piccolo et al., 2017). Studies of children and young people show that emotional concerns tend to be presented as cues rather than as clear concerns (Vatne et al., 2012), and physicians often reply with medical information rather than responding to emotional cues (Korsvold et al., 2016). However, patients are more likely to reply with more explicit concerns if the physician asks directly about their worries.

4.3 Self-management and Health Literacy

The term self-management has lacked consensus on a common definition for both adults and children (Modi et al., 2012), although it is frequently used in healthcare in association with how a person manages the health challenges of chronic diseases. Non-adherence to treatment is suggested to be a considerable concern among children and adolescents with chronic conditions, and children with RDs will therefore require attention to their self-management throughout their lifespan. While the concepts of adherence and self-management are interrelated and sometimes used interchangeably, self-management is broader and includes the interaction of health behaviors and related processes not only in the individual, but also in relation to the family, society, and the health care system (Modi et al., 2012). Increased attention to self-management requires the development of health literacy to improve health services and reduce health inequalities in society. Health literacy is a term that includes both personal and relational aspects concerning a person’s ability to acquire, understand, and use health information essential for self-management, and it should be viewed as a life-long learning process (Batterham et al., 2016; Bröder et al., 2017). The concept of health literacy appeared in the 1970s, focusing on people’s capacity to read and understand written information; however, it developed to become a multidimensional concept concerned with people’s ability to meet complex healthcare demands (Batterham et al., 2016; Sorensen et al., 2012). The word *literacy* refers not only to individual knowledge, but also to contextual, socio-cultural, and economic growth (Sorensen et al., 2012). Health literacy must be a shared responsibility between patients, HPs, organizations, and health-care systems. The increasing research on health literacy has so far largely been directed at the individual, which may place the burden on protecting and improving health solely on the individual and not on the government. During childhood, the development of cognitive, physical, and emotional processes takes place, as well as advances in health-related skills and behaviors that follow young people throughout their lives. Health literacy in childhood may provide benefits on the individual, community, and societal levels, and may empower children to engage in their health, to seek and use information, and to be reflective of their future choices (Bröder et al., 2017).

A common problem in research is that the development of interventions is not always connected to the needs of those receiving the intervention (Batterham et al., 2016). The intervention will often disappear when the study is over because the stakeholders were not included to take responsibility. The first step in optimizing a more systematic approach to health literacy interventions includes qualitative research and surveys to assess the needs (Batterham et al., 2014). To date, children's involvement in research on their own self-care has been less apparent than parents' participation on behalf of their child. However, promising studies on children's health literacy are emerging (Shih et al., 2016). Most children are more familiar with technological advances and the use of social media than adults, which may provide a useful platform for exchanging knowledge and developing programs for self-management. The "iPeer2Peer Program" is an example of an intervention that successfully improved self-management in adolescents with JIA, providing peer support and education via Skype calls (Stinson et al., 2016).

4.4 Patient Education

Health pedagogy and patient education are concepts that have developed in association with patients' self-management of their chronic diseases, often provided by the learning and mastery services in the specialist health services and in the municipal health and care services (Vågan et al., 2016). HPs have shared concerns about patients' ability to acquire, understand, and use health information to adhere to treatment (Batterham et al., 2016). Most research on health education has so far been limited to group-based programs, and few studies have investigated what kind of competence HPs need to improve patient's self-management (Vågan et al., 2016). However, some competence areas may be included in patient education, such as professional expertise on diagnosis and treatment, communication skills, knowledge of coping and coping strategies, and personal qualities and attitudes (Vågan et al., 2016). To deliver sufficient patient education, the nurse must master a variety of practical skills, such as the assessment of patients' educational needs and barriers to learning.

Adult patients with RDs seem to improve disease knowledge and management when receiving education from a nurse (van Eijk-Hustings et al., 2012). HPs can obtain knowledge of pediatric RDs on diverse websites, such as the Paediatric Rheumatology International Trials Organization (PRINTO) and the Norwegian National Advisory Unit of RDs in Children and Adolescents (NAKBUR). However, none of these sources has explicitly been concerned with children's and parents' challenges regarding the administration and experience of long-term needle injections. Patient education involves nurses taking care of the child's and parents' fear of needles, teaching the injection technique, and providing relevant knowledge about managing the disease. Nurses should also teach parents how to comfort their children during needle injections (Bauchner et al., 1994). Traditionally, nurses have based patient education on their assumptions of patient needs rather than individual assessment, which may mean that the education is incomplete or irrelevant (Kelo et al., 2013). Empowering education, contrastingly, implements child-and family-centered care and interactive methods for education and evaluation. Newly qualified nurses often feel overwhelmed by the responsibility and how much there is still to learn, but despite a steep learning curve, they feel proud to become qualified nurses and report a real will to do the best job possible (Duchscher, 2009). Nurses have an individual responsibility to provide patient education for children and parents, but it is a major concern that nurses seem to lack pedagogical competence and necessary support from their management (Bergh et al., 2014; Pascale Blakey & Jackson, 2016).

4.5 Peplau's Theory of Interpersonal Relations

Hildegard E. Peplau (1909–1999) constructed the middle-range nursing theory of interpersonal relations (Gastmans, 1998). Her nursing theoretical perspectives still seem relevant for reconciling and understanding some of the concepts in this study, and discovering Hildegard Peplau was a kind of a revelation for me. Peplau's (1952) book *Interpersonal Relations in Nursing* was a pioneering work, published without a physician as a coauthor, which was unheard of as a nurse in the 1950s. She struggled to make nursing an autonomous profession, distinct from medicine (Peplau, 1952), at a time when the nurse's job was seen merely as a handmaiden to the physician (Gastmans, 1998). Although Peplau's (1952) theoretical perspectives had an enormous influence on nursing, many of her later papers were not published or were not easily available until O'Toole and Welt (1989) complied, edited, and published her work in 1989. Her framework has guided nursing education and practice in many fields, particularly psychiatric nursing (D'Antonio et al., 2014). In her research, Peplau (1952) used a combination of induction (observation and classification) and deduction (application of theoretical concepts) methods, and her discussions about theory always had tight bounds to clinical practice (Gastmans, 1998; O'Toole & Welt, 1989). The theory of interpersonal relationships emphasizes the nurse–client relationship as the foundation of nursing practice. Self-awareness, personal identity, and individuality were established as central concepts to guide nursing, and she encouraged nurses to reflect and change and to influence the patient's learning (D'Antonio et al., 2014). She encouraged nurses to increase awareness of what they communicate to patients, both verbally and non-verbally, through an analysis of their own behavior (Peplau, 1997). Some of Peplau's (1952) ideas and writings are timeless truths that help nurses move away from a reductionist focus on disease and toward an orientation of an individual's experiences in the context of family and society (D'Antonio et al., 2014). Peplau (1952) stated that nursing should aim to reduce patient's dependence and encourage them to become autonomous by assisting their choices (Gastmans, 1998). These thoughts fit well with the term self-management. She stated that the nursing process is educative and therapeutic when the nurse and patient share a mutual understanding of the patient's problems and collaborate to find a solution, similar to the modern concept of shared decision-making. Peplau (1952) emphasized the complexity of nursing and considered being an educator as important a role for nurses as caring for sick patients (Gastmans, 1998).

To develop professional relationships with patients, Peplau (1952) recognized that nurses need different roles that are dynamic and flexible (cited in Simpson, 1991). A role contains a set of norms that the nurse can use in different situations to interact with the patient in a cooperative and mature way. Peplau (1952) defined six different nursing roles: *the role of stranger, the role of resource person, the teaching role, the leadership role, the role of counselor, and the surrogate role,* and she gave advice on how to handle each of these roles. Nurses should be able to shift between the various roles and skills developed in clinical practice under competent supervision (Peplau, 1952). The theoretical framework of Peplau

(1952) describes the development of the nurse–patient relationship through four phases, which were later revised to three phases: (1) In the orientation phase, the nurse should focus on the patient and collect information about the patient's needs through interviews, history taking, and assessment; (2) the working phase should account for most of the time in the nurse–patient relationship; and (3) the termination phase includes the patient's transition from hospital to community life. The nurse should teach patients about handling symptoms and challenges at home; Peplau viewed the third phase as a "freeing process" (Simpson, 1991).

Human communication, professional attitudes, information, and a caring involvement are described as central concepts in Peplau's caring relationship (Gastmans, 1998), and seem to have found renewed relevance in concepts such as *patient-centered care*, often considered standard in modern healthcare (D'Antonio et al., 2014). Many of Peplau's concepts are fundamental for the nurse–patient relationship, promoting health and well-being. She emphasized that nursing should never be provided as only an expert activity based on a technique. Peplau understood nursing as a practice-based science founded on the relationship between nurse and patient and emphasized the connection between theory, research, and practice (Gastmans, 1998).

5. Research Design and Methods

This chapter provides an overview and explanation of the methodology of the thesis, including the choice of design and methods.

5.1 Literature Review

The empirical basis of the thesis builds upon findings in current research up until 2017. The initial literature searches of pediatric needle-related pain and fear were conducted using a specialist librarian in the electronic databases CINAHL and MEDLINE (PubMed) (Ovid), with subject headings and truncated keywords. Terms and keywords used in the first searches were *procedural pain*, *fear of pain, needle fear, child–parent–nurse relation,* and *parental role*. An alert search was set up in PubMed from the National Center for Biotechnology Information (NCBI) at the U.S. National Library of Medicine (NLM) with the term "*fear of needle pain*," which resulted in several alerts throughout the study. The literature search was updated several times, and the searches were extended with terms such as *communication, coping, health literacy, health pedagogy, nurses' educational role, patient education, pediatric rheumatic diseases*, and *methodological literature*. The theoretical perspective and concepts were determined after the onset of the study based on continuous analysis and interpretation of the findings. An updated literature search included searches in Psych INFO, Cochrane Library, and the Web of Science for cited references. By receiving alerts from PubMed and by following significant researchers on Research Gate, I have kept updated on current research on the topic. A specialist librarian assisted with an updated literature search in April 2021, with the same terms and keywords as in the first search, combined with *patient education.* This resulted in 187 references, of which 21 were considered relevant to the thesis.

Table 1: *Overview of Selected Studies from the Updated Literature Search in April 2021*

Author, Year	Design	Intervention/Population	Results
Birnie et al. 2018	Systematic review including RCTs Cochrane	Psychological interventions for needle-related procedural pain and distress in children aged 2–19 years Distraction (n = 32), CBT (n = 18), hypnosis (n = 8), information (n = 4), breathing (n = 4), suggestion (n = 3), memory alteration (n = 1) vs. standard care	The review included 59 studies of 5,550 participants during venipuncture, intravenous insertion, and vaccine injections. Evidence supports the efficacy of distraction, hypnosis, combined CBT, and breathing interventions for reducing

			children's needle-related pain or distress, or both. Low-quality evidence
Van Dijkhuizen et al., 2018	Development of a questionnaire Distributed to 25 countries—entered on the PRINTO website	Completed by 622 parents in 23 countries; 66.7% of patients were female, with a median age of 10–11 years.	Many patients lack detailed information and follow-up. It is important to improve doctor–patient communication between visits.
Heden et al., 2019	Clinical-based cross-sectional	90 children aged 7–18 years. Self-report of pain and fear on a 0–100 mm visual analogue scale (VAS) during needle insertion into a subcutaneously implanted intravenous port following topical anesthesia.	The needle-related fear level was reported to be as high as the needle-related pain level. Younger children reported their fear levels to be higher than their pain levels.
Pavlova et al., 2020	A narrative review	Despite being a robust predictor of future pain and distress, memories of past painful experiences remain overlooked in pediatric pain management.	Children's pain memories are malleable and can be reframed to be less distressing, thus reducing anticipatory distress and promoting self-efficacy. Parents can alter children's pain memories to be less distressing by talking, or reminiscing, about past pain.
Roszkiewicz et al., 2020	Prospective, two-sequence crossover study	23 patients with JIA already treated with subcutaneous MTX (prefilled syringes) Comparing ease of use, frequency of therapy side effects, injection-site pain, and parent/patient preference of prefilled syringes with prefilled pens	82.6% patients and their caregivers preferred prefilled pens. Injection with the pens was less painful than syringes ($p < .01$). Side effects of MTX were less pronounced ($p < .01$).
Stinson et al., 2020	RCT, comparing the Teens Taking Charge web-based program to a web-based education control condition	Enrolled 333 adolescents aged 12–18 and 306 caregivers Followed a 12-week program Outcome assessment occurred at baseline, at 12 weeks (post-treatment), and at 6 and 12 months post-randomization.	Significant reductions in pain intensity ($p = .02$) and pain interference ($p = .007$) in the intervention group and significant improvement in HRQL related to problems with pain ($p = .02$) and problems with daily activities ($p = .01$), sustaining over time
Gates et al., 2020	Systematic review Including quantitative studies	Determining the effect on pain and distress in children using digital technology distractors 106 studies (n = 7,820) reported on e.g., virtual reality and video games, used in common procedures (e.g., venipuncture, dental, and burn treatments)	For painful procedures, digital distraction resulted in a modest but clinically important reduction in self-reported pain. Its superiority over nondigital distractors has not been established.

5.2 Research Design

This study explores the experiences and practices of children, parents, and nurses with needle injections during training at a hospital and in their natural sociocultural environment. A qualitative explorative design was chosen to examine and understand relevant phenomena, e.g. attitudes, behaviors or concepts, rather than quantifying them (Creswell, 2014; Green & Thorogood, 2018; Moen & Middelthon, 2015). There are several methods for approaching qualitative research, all of which involve systematic data collection, organization, and interpretation of transcribed material from talk or observation (Malterud, 2001).

5.3 Overview of the Three Sub-Studies

Video observations were found to be the most appropriate method for initiating the study, allowing investigation of social actions and interaction in a natural context (Heath et al., 2010). Individual interviews and focus groups were added to achieve rich descriptions of the children, parents, and nurses' experiences of the processes of learning and teaching management of long-term injection treatment at home (Green & Thorogood, 2018).

Table 2: *Overview of the Three Sub-Studies, the Source for Data Generation, and the Analytic Approach for Each Sub-Study*

Sub-Study	**Method**	**Data Source**	**Analytic Approach**
I	Video observations of children, parents and nurses during the first injection and training session followed by a short interview.	Video recordings from 9 training sessions with 8 children (5–15 years), 11 parents, and 7 nurses and short interviews in a pediatric ward. Field notes	Thematic Analysis (Braun & Clarke, 2006; Terry et al., 2017) and Interaction analysis (Jordan & Henderson, 1995)
II	Individual interviews with children and parents 4–6 month after the first injection. Focus groups with children and parents with minimum 6 month experience with injections.	Audio recordings from individual interviews with 7 children and adolescents (6–16 years) and 8 parents. Four focus groups with 9 children and adolescents (11–17 years) and 8 parents. Field notes	Thematic Analysis (Braun & Clarke, 2006; Terry et al., 2017)
III	Focus groups with nurses working in one pediatric ward and two outpatient clinics	Audio recordings from three focus groups with 14 nurses. Field notes	Thematic Analysis (Braun & Clarke, 2006; Terry et al., 2017)

5.4 Setting

The main part of the study was conducted at a university hospital in the southern part of Norway, with the regional responsibility of diagnosing and treating children with RDs. According to the head of the rheumatology department, approximately 40–50 children (aged 1–18 years) are diagnosed with an RD at this hospital each year. An increasing number of children are offered injection-based treatment, which implies a need for education to help patients and their families manage the therapy at home. Some children start with oral medication and switch to or add subcutaneous injections to the treatment, while others initiate treatment by injection. Most of the children at the time of the study had short-term hospitalization in a pediatric ward, while others received their first injection and patient education at the outpatient clinic. The children usually received treatment follow-up at the outpatient clinic. The pediatric ward was also responsible for children with neurologic and allergic diseases. The physicians specialized in the field of RDs, but the nurses usually cared for all the children in the ward. We also invited a university hospital in northern Norway to participate in sub-study III. In their practice, injection training was mainly provided at the outpatient clinic.

All the video recordings in sub-study I were conducted in the children's bedrooms of the hospital ward. The children and parents participating in the follow-up study (sub-study II) could choose whether the individual interview should take place in their homes or at the hospital. One of the focus groups was held at the locations of the Norwegian League against Rheumatism, while for practical reasons, the others were carried out at the two hospitals included.

5.5 Sample

Sixteen children, eighteen parents, and nineteen nurses participated in the study. A purposive sample was chosen to provide the data needed to answer the specific research questions. The sample was relatively small but intended to include information-rich cases for in-depth study (Green & Thorogood, 2018) and was justified by the concept of information power rather than reaching data saturation (Malterud et al., 2016).

5.5.1 Inclusion criteria

We aimed to obtain variations in our sample to explore different interactions, perceptions, and behaviors among the participants, but within some predetermined criteria. The inclusion criteria for sub-study I were children diagnosed with an RD and in need of education for self-administration of subcutaneous injections at home. The children had to have age-appropriate cognitive development and be able to speak Norwegian. We assumed that the most available children would be between the ages of 5 and 12 years. However, when we piloted the study, we realized that older children also experienced injection-based treatment as challenging. Therefore, we reapplied to the South Eastern Regional Committee for Medical and Health Research Ethics (REK) and received permission to extend the age limit to 16 years. The adults were parents or caregivers following the child in the training session, and nurses provided the first injection and education.

The inclusion criteria for the individual interviews in sub-study II were children and parents who had participated in sub-study I and were willing to participate in the interviews. The participants in the focus groups were children with RDs, aged 10–19 years, and with experiences from injection-based treatment for more than six months. The age span among the children in the focus groups was limited to three years and had to include at least three participants who could meet at the same time. The parents in the focus groups had to be parents of children with RDs, and have more than six months of experience with injection treatment. Parents could participate even if their child did not participate, and vice versa.

Inclusion criteria for participating in sub-study III were nurses having experience with patient education and administration of subcutaneous injections to children, preferably with RDs, and were willing to participate.

5.5.2 Recruitment

Before the onset of the study, a chief physician and an experienced nurse provided me with background information about the treatment of children with RDs and the context of the treatment. Based on their information and input from the user participant, we developed written information about all parts of sub-study I for relevant HPs in the department. Furthermore, we arranged several meetings with the nurses to give them the opportunity to ask any questions about the study, and the nurses were able to give their preliminary consent to participate. The research assistant on the ward kept an overview of available nurses and ensured that only those who had agreed to participate were invited to participate when the children who were eligible for the study arrived. Then, a nurse willing to participate asked eligible children and parents if they wanted information about the study. If they agreed, I met with the potential children and parents and provided in-depth oral and written information about the study. Oral and written consent was obtained from the participants before the training session began.

At the end of the video sessions, the parents were informed about a follow-up interview (sub-study II) and were asked for permission to contact them after four to six months. All the parents agreed, and they were willing to participate in individual interviews when they were re-contacted. We decided on the time and place for the interview by phone. One family living far away from the hospital preferred to contact me when they arrived for control, but I did not hear from them again. Written information, consent, and topics for the interview were sent by e-mail so that children and parents could prepare and make the final decision about participating.

The Norwegian Rheumatism Association for Children and Adolescent (BURG) and NAKBUR assisted in recruiting participants for the focus groups (sub-study II). BURG made announcements on social media and contacted its members. NAKBUR gave oral and written information at a weekend gathering for adolescents and parents. We also announced the study on the hospital’s website. A research assistant at the ward and the outpatient clinics recruited nurses willing to participate in the focus groups (sub-study III). In addition to taking care of children with RDs, the nurses at the outpatient clinics had a broad range of treating patients. Therefore, we included nurses with experience in patient education and administering injections to children with diabetes and immune deficiencies to achieve nuanced and broad discussions about the nurses’ educational role in the groups.

Table 3: *Characteristics of the Final Sample*

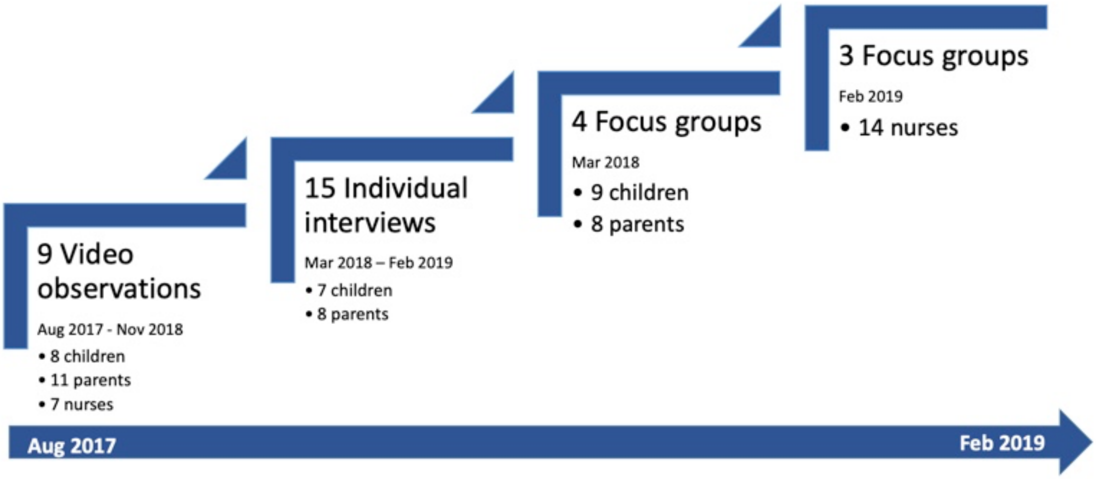
		Sub-Study 1	Sub-Study 2		Sub-Study 3
		Video Observations	Individual Interviews	Focus Groups	Focus Groups
Participants: number (gender F/M)	C	8 (6/2)	7 (5/2)	9 (6/3)	
	P	11 (6/5)	8 (7/1)	8 (5/3)	
	N	7 (7/0)			14 (14/0)
Age: median (range) Y	C	12 (5–15)	12 (6–16)	14 (11–17)	
	P			46 (34–55)	
	N	27 (26–34)			40.5 (24–64)
Experience with injections: mean (range) Mo–Y	C		5.6 Mo (4–6 Mo)	8.1 Y (6 Mo–15 Y)	
Years of nursing experience: median (range)	N	9 Mo (3Mo–4 Y)			9.5 Y (1–41)
Education: RN/ pediatric nurse/other (number)	N	2/5/0			6/4/4
Duration of each session, interview or focus group: mean minutes (range)		17 (6–31)	37 (12–62)	74 (45–100)	80 (70–90)

Children = C, Parents = P, Nurses = N, Female = F, Male = M, Month = Mo, Years = Y

5.6 Data Generation

Despite the broad orientation to methodology in qualitative research, many researchers share common concepts, such as commitment to naturalism, reflexivity, a focus on meaning, a flexible approach to research strategy, and a critical approach (Green & Thorogood, 2018). The preference for this study was an orientation toward naturalism, seeking to explore the participants in a real-life context (Green & Thorogood, 2018; Silverman, 2014). Therefore, the data were generated through video observation of real training sessions in a hospital ward and by talking directly to participants in individual interviews and focus groups instead of offering them questionnaires. These methods provided access to language and behavior and served as significant information sources. Figure 1 illustrates the timeline of the data collection period.

Figure 1: *Overview of the Timeline for Data Collection*



5.6.1 Video observation

Observation is rooted in an ethnographic tradition where the researcher traditionally spends a lot of time with the participants and becomes part of the setting to understand the world of the inside, providing a rich, detailed description of social practice (Green & Thorogood, 2018; Silverman, 2014). A pilot observation of one training session indicated that the procedure would take place at a fast pace and contain many details of the participants' talk and actions. These actions and interactions would be practically impossible to discover by observing directly in situ and taking field notes, which is the standard procedure for participant observation (Green & Thorogood, 2018). Using video observation allowed me to collect observational data of ongoing social activities and interactions in a detailed way (Knoblauch & Schnettler, 2012); video observation is considered an ideal method to generate data without breaking into the child-adult interaction. Video data allow complex phenomena and social interactions to decompose into smaller entities, enabling a microanalysis of interactions (Heath et al., 2010; Jordan & Henderson, 1995).

The preparation with a pilot observation and information from the research assistant revealed the importance of using flexible equipment. Engineers from the Teaching Learning Videolab (TLVlab) at the Faculty of Educational Sciences at the UiO provided invaluable guidance with the preparation of equipment, as video observation is a method often used in the research of schoolchildren in Norway. It was important to use video cameras that were easy to prepare and to capture close-up images of the faces and an overview of the whole situation (Heath et al., 2010). The TLVlab recommended using two Go-Pro cameras placed at two different angles and an additional recorder to secure good sound quality. The equipment was pilot tested in empty patient rooms, and the quality was discussed with engineers. I was present in the room during the training session to start the recordings at the beginning of the procedure, to pause the recording if needed, and to switch off the recording when the nurse signaled that the procedure had ended. The field notes collected during the procedure aimed to conceptualize the context and actions that could take place out of reach of the video recordings. Short interviews directly after the procedure allowed the participants to reflect on the experience of being recorded, and enabled the children to express their experiences of pain and fear. The data from the short interviews and field notes were included in the total data material and used to substantiate the findings of the video observations.

5.6.2 Individual interviews

Interviews used in research are a professional conversation that constructs knowledge about a specific topic through an interaction between the interviewer and the person being interviewed (Moen & Middelthon, 2015). Memories and experiences are both constructed through narratives and discourses, and are seen as occasions for the *production (generation)* of data and insights (Atkinson & Coffey, 2003). From such a perspective, knowledge is co-constructed through several processes of reflection and articulation that involve both the interviewer and the interviewee. The articulation of speech is more than a verbal expression, and it was important to note the tone, language, and metaphors used in the interviews. The participants also make continuous reflections when listening to their own stories while being interviewed (Moen & Middelthon, 2015).

We aimed to facilitate a natural conversation and make the participants feel relaxed and empowered. Thus, the interview guides were developed and adapted for children of different ages and parents. The main topics in the interview guides were sent by e-mail in advance of the interview. The interviews with the children were conducted separately from their parents, except for the two youngest children who preferred to have their parents present. All participants were offered to conduct the interviews at home, something 10 out of 15 preferred to do. Five participants preferred to implement the interview during a follow-up at the hospital, while one family invited me to attend the injection procedure at home. All the children showed greater confidence during the interview than in the first meeting before the first injection. They spoke with a higher and clearer voice and were eager to share their stories. Contact was established by talking about the child's everyday life, and the children were invited to draw, write, or puzzle during the interview. In two cases, the adult participant was the parent other than the one who had attended the video observation. In one case, both the mother and father participated, but they were interviewed separately. The individual interviews were audio recorded, and a field note with the main impressions was written immediately after each interview.

5.6.3 Focus groups

The focus groups were not planned in the first protocol, but shortly after the onset of the study, we considered that more variation in the data material would be valuable for the study. As focus groups can discover how people think, they were considered a suitable method to gain insights into the children's and parents' experiences with long-term injection-based treatment at home, as well as the nurses' perceptions of providing injections and patient education to children. Rather than asking questions, as in an interview, the group discussion is facilitated by a moderator who encourages the participants to mutually interact to generate data (Green & Thorogood, 2018; Krueger & Casey, 2015). Participants with similar characteristics were grouped to discuss a topic of common interest. Each group was scheduled to last 45–60 minutes, and we planned to discuss seven different topics with the participants. In case some of the children preferred to express themselves in ways other than talking, drawing and writing equipment were made available (Kirk, 2007). We invited the user participants to join the focus groups with the children to make it easier for them to share their stories. The session with the youngest children started by playing a get-to-know-each-other game, and we served some light refreshments, pizza, and soft drinks in all groups. I took the role of moderator and used previous experiences in interactions with children and adolescents. Two of the supervisors acted as secretaries in their respective focus groups, as they had extensive experience with this method. All focus groups were audio recorded, the secretary wrote field notes during the focus groups, and we discussed the main impressions immediately after each group. The transcribed audio recordings, field notes, and notes of the main impression established the overall data collection.

5.6.4 Background information

To conceptualize the data, we collected some background information. Demographic data collected from the children's patient journal included age, diagnosis, duration of the disease, and medical treatment. We also asked for the contact information of parents who agreed to be invited to participate in sub-study II. The nurses who participated filled in a short form that obtained information on their age, experience as nurses and with administering needle injections to children, and additional education. All participants in the focus groups completed a short form to obtain their demographic data, such as age, diagnosis, duration of the disease, and medical treatment, adjusted to whether they were a child, parent, or a nurse.

5.6.5 Data management

All research data were stored securely at the University's Service for Sensitive Data (TSD). The procedure was to immediately transfer the data from the video and sound recorders into an encrypted computer before uploading them to TSD. The data on the recorders were deleted immediately after transfer, and the equipment was stored in a locked cabinet at the hospital after each video observation. The data were only available to the Ph.D. student and two of the supervisors through a secure login to the server. Demographic data about the participants were stored separately from the research data in a secure safe.

5.7 Data Analysis

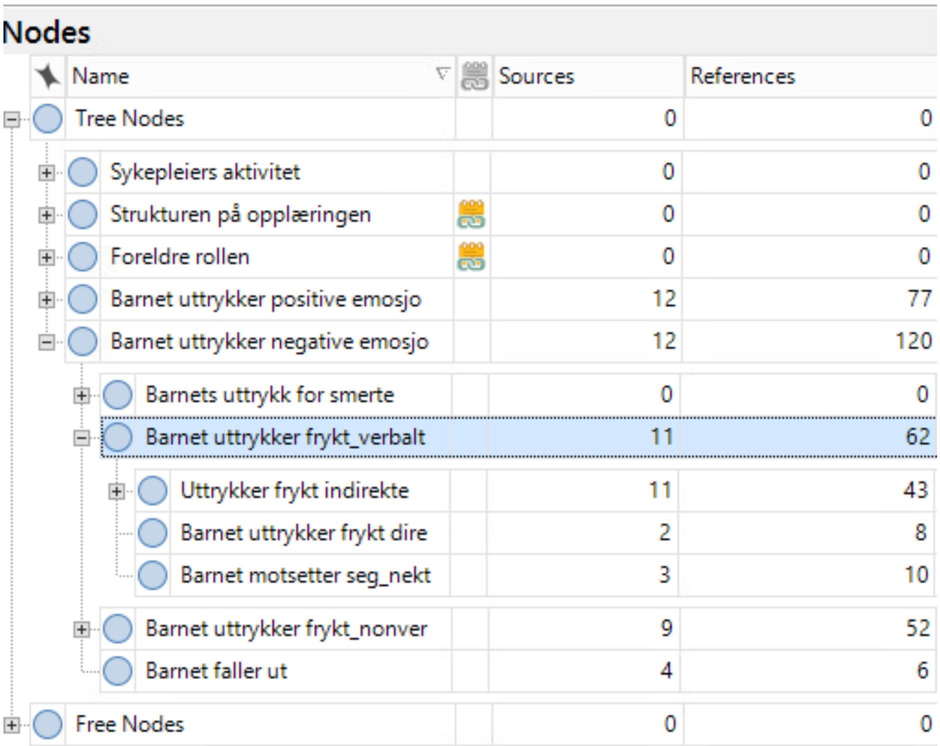
The analysis followed the six phases of Thematic Analysis (TA) (Braun & Clarke, 2006; Terry et al., 2017), which were found to be a useful and flexible method for the main analysis in the three sub-studies. Table 4 provides an overview of common actions in each phase and the differences between the sub-studies.

Table 4: *Description of the Actions in Each Phases of the Thematic Analysis*

Phases	Video Observation	Individual Interviews and Focus Groups
1. Familiarization with the data	Transcribe verbal and nonverbal communication. View the videos in the research group sessions. Read the transcribed text and field notes several times. Make annotations and memos in NVivo.	Transcribe verbal communication. Read the transcribed text and field notes several times. Make annotations and memos in NVivo.
2. Generate initial codes	Identify children's, parents', and nurses' behavior and talk by creating meaningful labels (codes/nodes). In cooperation with the main supervisor.	Identify meaningful labels of the participants' talk (codes/nodes). Apply the identified codes from the individual interviews deductively to generate codes in focus groups, with an open mind to discovering new codes. Code each focus group with nurses inductively. Search deductively through the whole material for the codes used.
3. Search for themes	Look for patterns across the dataset, and construct candidate themes. Use NVivo to view coding stripes, compare nodes, explore hierarchy charts, and develop preliminary thematic maps.	
4. Review themes	Shape, clarify, and reject themes to ensure that they work well in relation to the coded data, the dataset, and the research question. A cooperative process in the research group.	
5. Define and name themes	Moving from a summative position to an interpretative orientation. Developing a final thematic map. A cooperative process in the research group.	
6. Produce the Report	Create a final report that summarizes the findings and the connection to previous literature, and present a selection of quotes to make the report clear and understandable. A cooperative process in the research group.	

TA appears as a linear, six-phased method, although it really is an iterative and reflective process developing over time with a continuous movement back and forth between the phases (Nowell et al., 2017). The analysis in all three sub-studies was based on an inductive approach, which means that themes and patterns were built from the bottom up by structuring the data to gradually become more abstract elements of information (Creswell, 2014). The process worked back and forth between the preliminary themes and the database until the whole research team agreed on a complete set of themes. Furthermore, it was necessary to look back on the data and deliberate on whether more data could support our themes or whether some themes contained the same information. This process provided the possibility for deductive thinking, even though the analysis had started inductively (Creswell, 2014). TA has limited power unless one moves from the descriptive presentation of the findings to an interpretative orientation (Braun & Clarke, 2006; Terry et al., 2017). Therefore, we interpreted and discussed the defined themes in light of previous research and theoretical perspectives anchoring the analytical claims in our analysis. The software tool NVivo 11 was useful for obtaining a systematic organization of the data and assisting the analysis (Richards, 2015). Among the several functionalities of NVivo, viewing the coding stripes, comparing nodes (codes), and exploring hierarchy charts were most beneficial when searching for patterns across the dataset. In the NVivo program, codes are called nodes and can be grouped in a tree structure, as the example in Figure 2 shows.

Figure 2: *Example of the Organization of Nodes (= codes) in NVivo*



Nodes

Name	Sources	References
Tree Nodes	0	0
Sykepleiers aktivitet	0	0
Strukturen på opplæringen	0	0
Foreldre rollen	0	0
Barnet uttrykker positive emosjo	12	77
Barnet uttrykker negative emosjo	12	120
Barnets uttrykk for smerte	0	0
Barnet uttrykker frykt_verbalt	11	62
Uttrykker frykt indirekte	11	43
Barnet uttrykker frykt dire	2	8
Barnet motsetter seg_nekt	3	10
Barnet uttrykker frykt_nonver	9	52
Barnet faller ut	4	6
Free Nodes	0	0

5.7.1 Analysis of the data for sub-study I

The initial analysis followed the phases of TA (Table 4) and resulted in a descriptive presentation of the children's expressions of pain and fear, the adult talks and actions, and the structure of the training session. The coding process was inspired by previous research describing how children's negative emotions can be shown indirectly as cues rather than explicit concerns (Vatne et al., 2012; Zimmermann et al., 2011).

Interaction Analysis (IA) was used for in-depth exploration and interpretation of the interactions and communication between the nurse, child, and parent(s) (Jordan & Henderson, 1995). IA is a method for empirical investigation of human activities, such as talk and nonverbal interaction, so that routine practices and challenges can be identified, and resources for a solution may be discovered. Group work is essential in IA, and all members of the research team viewed the videos and met several times to discuss our interpretations throughout the analytic process. Collaboration viewing is powerful at neutralizing preconceived notions from team members so that one also discovers something other than expected (Jordan & Henderson, 1995). IA allows different foci for analysis, and we chose to identify and explore *events* in the videos in which the child showed signs of distress. We carefully examined the content of the interactions to identify patterns that influenced the children's actions and reactions. The interpretation from the IA resulted in three types of communication that affected the children's emotional expressions differently. Table 5 shows an example of the manual work with IA.

Table 5: *Example of the IA when exploring "The adults' responses to the child's fear"*

Time	Verbal Talk	Action	Codes	Preliminary Themes	Interpretation
13:59	N: "We will make this together." P: "It is not so difficult to insert the needle." C: "Here?"	C: Breathes heavily, dries tears, leans over her thigh with the syringe in the hand N + P: leans over the child to find an injection site C: withdraws, cries, holding hands in front of the face	Non-verbal fear; body, face, cry Reassurance, try to motivate The child tries to understand	C: Non-verbal fear N: Awareness of fear N: Relate to the parent N: Being an instructor C: Being engaged P: Supports the nurse's activity	The child is motivated, very afraid, but tries to become engaged The nurse is aware of the child's fear, but focuses on the technique The parent supports the nurse N + P use reassurance

14:18	P: "Isn't it easier like this?" N: "Yes, if you hold it like this." P:" Shall I help you to hold the syringe?" C: "uhmm" P: "Like this?" C: "No." P: "Do you know what? This is going to be okay. You will feel a little stick, and then it's over. It might hurt just a little bit—maybe." N: "Blood tests hurt more." P: "Yes." C: "Ahh."	C: Cries more, moaning, wipes tears, tries to take the syringe again C: Nods, looks at the thigh and syringe P: Takes the child's hand, leads it toward the thigh and syringe C: Leans against the parent P: Holds a supporting arm over the child's shoulder N: Nods	C: Body, face, cry—fear C: Tries to understand C: Resists Reassurance P: Comfort, physical support C: Agrees	C: Non-verbal fears C: Wondering and engaged N: Instructor P: Supports the nurse C: Verbal fear P: Supports the child's emotions N: Relates to parent C: Consents to injection	The child tries to get engaged. Parent and nurse are moving forward too fast Child needs time (space)—opposes Child gets emotional support (from parent) Reassurance from N + P (Duplex message—ambiguous) Child gives up resisting
15:01 15:21	C: "I don't want to have it (the needle) inside for a long time" P:"No, we will count to max 10—wasn't it?" N: "Yes, max 10." C: "But should I insert the needle first?" P: "You must first insert the needle, and then you can push." N: "Do you want me to hold, so you and Mom can take the injection?" C: "uhh"	C: Straightens up and wipes away some tears P: Looks at the child and the nurse. N: Nods C: Looks at the nurse, dries tears and groans N: Nods (tries to say something) C: Cries more again, looking very sad, and leans toward the parent	C: Involved P: Suggests coping strategy N: Suggests technical support C: Verbal + non-verbal fear	C: Engaged P: Supports the child's emotions N: Instructor C: Verbal and non-verbal fear	The child suggest coping strategy—how to do it Gets support from adults—planning details Child needs support from nurse (looking at her when asking) Nurse continues to focus on the technical part. The child's fear increases again (loses heart)

C = Child, P = Parent, N = Nurse

5.7.2 Analysis of the data for sub-study II

Sub-study II was based on data obtained from both the individual interviews and the focus groups with the children and the parents. The prepared topics and questions were similar for all participants, but the answers and discussions developed slightly differently in the focus groups compared to the individual interviews. The appendices include examples of interview guides for the individual interviews and topics for the focus groups. The analysis followed the descriptions of the TA, as described in Table 4. The software program f4 Transcript was used for writing the transcriptions, and NVivo 11 was used to organize the data and the analytic process. We assessed the field notes (exemplified in Table 6) and notes from the secretary in the focus groups alongside the transcriptions from the individual interviews and the focus groups. The analysis of sub-study II involved a more explicit inductive-and-deductive-data analysis (Creswell, 2014); initially, the individual interviews were coded inductively, and these codes were used deductively to code the dataset from the focus groups. The entire research group gathered, discussed, and agreed on the preliminary themes and patterns. The process was developed further by going back (inductively) from the bottom in the FG and identifying new codes for which we again searched (deductively) in the individual interviews.

Table 6: *Example of a Field Note Written Immediately after an Individual Interview*

The surroundings

Visit at home with mother and son.

Cozy, candlelight, offered fruit and drink (to me)

I had prepared to show the film from the training session, but I changed my mind because I thought it would interfere with the interaction

Interview with the child

Speaking with a distinctly loud voice, which was low during the training session—with many thoughts to share

The child gave additional information after I had finished the interview.

The medication was effective, but with side effects? (Could it have been another drug?)

Took the injections alone

Appreciate the mother's care (piece of chocolate as a prize)

I forgot to ask where the injections are done (mom said it was always in the bathroom, alone with no one watching)

Interview with the mother

She was eager to share her story.

She had not received any training (the child was the expert) + some info from dad

She lacked follow-up—not enough with one training for the child

She spoke about the injections first—then about life and the disease

Little support from physicians (feeling of despair)

My reflections

The mother is very open, considering we had not met me before. Seems relieved to tell her story.

Fatigue seems to be the main problem.

About 1 hour, 15 minutes in total. Good quality of the sound on the recorder.

Should have asked to speak to Dad? (who participated in the training)

It was very helpful to interview the mother. I obtained rich data.

5.7.3 Analysis of the data for sub-study III

The analysis was based on data from three focus groups with nurses and followed the steps in the TA (Table 4). The nurses worked under different conditions; their personal characteristics were somewhat different, and we performed the coding in several steps. First, we performed inductive coding of the data from each focus group, and then all codes were used deductively to search through the three different focus groups again. The organization in NVivo made it easy to count the times each code was used. Finally, the analysis showed that the nurses in the three focus groups had different foci in their discussions, as illustrated in Table 7. The different foci underpinned some of our conclusions described in the findings, for example, that the nurses had different preconditions for providing patient education in the ward and at the outpatient clinics. The research group agreed on the interpretation of the analysis.

Table 7: *The Most Frequently Used Codes in the Three Focus Groups with Nurses*

FG 5	FG 6	FG 7
Nurses' distress 11	Individual adaptation 12	Nurses' awareness of one's own competence 14
Communication with children 10	Pain and fear 8	Nonpharmacological 10
Nurses' skepticism and ambivalence 9	Nonpharmacological 8	Nurses reflections 9
Pain and fear 9	Aids used for training 8	Create security and positive experience 9
Restraint 8	Personal suitability and experience 7	The child's experience 8
Building a relationship 8	Gradual approach 7	Individual adaptation 8
Spending time 8	Parental involvement 7	Managing pain and fear 8
Education and course 7	Parental anxiety 7	Parental involvement 8
The child's experience 7		Communication with children 7

Note. A similar color illustrates the same code in the different focus groups (n = number of times coded).

5.8 Ethics

This study was designed and performed according to the Code of Ethics of the World Medical Association Declaration of Helsinki (World Medical Association, 2013). It was approved by

REK southeast (2016/1749, 2017/2194), and the Data Protection Officer at Oslo University Hospital and University Hospital of North Norway. The unit leaders approved the study in a clinical setting. Including children in research involves special ethical considerations, as described in Sections 5.8.1 and 5.8.2, and further discussed in Section 8.5.

5.8.1 Consent

The ethical principle of voluntariness to participate in research was followed, and all participants were informed of their right to withdraw from the study at any time without reason or penalty. Children aged between 16 and 18 years have the right to give their own consent to participate, as the research did not involve physical intervention or drug testing, while parents or others with parental responsibility must usually consent to the participation in research of children younger than 16 years (Helseforskningsloven, 2008). In this study, we obtained verbal and written consent from all nurses, parents, and children ≥ 12 years. Children ≥ 16 years gave their independent written consent, while children < 12 years gave their verbal consent. To accommodate all the participants, written information material was prepared and adapted to the different ages of the children, and to the parents and nurses. The appendices provide examples of written information and consent adapted to the various participants. As some children had only one parent present at the hospital, the ethical committee also approved obtaining verbal consent from the other parent at home before the procedure and obtained their written consent by mail afterward.

5.8.2 Vulnerability

Research on children's lives and well-being is important and valuable, but one must be aware of the vulnerability of the child (Backe-Hansen, 2009; Fossheim et al., 2013). The video recordings of the children's interactions with their parents and nurses when they received their first medical injection reflected particularly vulnerable situations for the child and parent(s), as well as the nurses. Therefore, I focused on providing the necessary information and preparation, for example, by talking to the child and parent(s) before their final decision about participating in the study. The short interviews with the participants after each video observation offered an opportunity for the participants to reflect on their participation in the study and for me to further explain and discuss situations that might need more follow-up. It was extremely important to take care of the nurses' integrity, as some nurses prior to this study had informed me that they were uncertain about how to perform the training and injection treatment. The information meetings before the study onset and the conversation immediately after each training session sought to reflect upon their experiences of participation. To create a safe environment for the participants and meet unequal power relations, the individual interviews took place in their homes, if they preferred. They received the topics for the questions in an interview guide in advance to enable them to be prepared, and I reminded them of their right to withdraw at any time without reason or penalty. As these children suffer from a chronic condition that may cause bad days, it was possible to reschedule the interview time, though this was only necessary once. Because of the relatively small sample and the risk of recognizing participants, the quotes used (in the published papers) retain the participants' anonymity by using some additional information, such as whether a quotation represents many or few participants, or by using fictive names.

5.9 User Involvement

Due to the risk of an unequal power balance between HPs and patients in patient education, user participation has increasingly been included in learning programs for patients and in advising clinical practice in general (Strøm & Fagermoen, 2014). User participation has also become increasingly common in research to produce knowledge that better benefits healthcare services (Haugen, 2013). From several financial institutions, it has become mandatory to include user participants to obtain funding. Although it may not be appropriate to include users in all types of research, we included user participants in this study from the very first stage of study planning. As this study planned to investigate children with RD, we applied for funding from the Norwegian League against Rheumatism to the Dam Foundation. The subgroup for children and adolescents in this organization, called BURG, recruited our user participant. The user participant was 17 years old at the onset of the study and had extensive experience with injection treatment for her RD. She read the preliminary project protocol, and we discussed the purpose of the study. She reassured me that this was an important topic to investigate. The user participant was involved in many parts of the study. At the onset of the study, we collaborated and published an article about the study on BURG's website. The user participant gave advice on the topics and questions for the individual interviews and focus groups and participated as a user participant in the focus groups with the children and adolescents. By sharing some of her own experiences, she inspired the participants to enter into the warranted discussion about their experiences. Later, she reviewed the preliminary results in sub-studies I and II and gave her view of our interpretation of the results. Her contribution to this study has been of great and invaluable importance.

6. Findings

This chapter summarizes the main findings from the three sub-studies. Table 8 provides an overview of the three sub-studies, including the aims and how the findings can be understood. Then, the main themes and findings of each sub-study are presented. Finally, a holistic understanding of the main findings of the study is presented across the sub-studies.

Table 8: *Presentation of the Summarized Findings in Each Sub-Study*

	Title of the Original Article	Aims	Understanding of the Findings
I	Children's fear of needle injections: A qualitative study of training sessions for children with rheumatic diseases before home administration	To explore children's expression of pain and fear during training sessions before home administration of subcutaneous injections To explore how nurses' and parent's communication affects children's expressed emotions	Children's fear of needles are more bothersome than the pain. Pain and fear can remain undetected if nurses do not assess and address these negative emotions. Children want to get involved. Nurses have opportunities to utilize children's resources and invite them to share decision-making. Adult acknowledgment of children's emotions may improve children's experience of needle injections. Nurses' attention to technical instructions may impede focus on children's emotional needs.
II	'I don't want to think about it': A qualitative study of children (6–18 years) with RDs and parents' experiences with regular needle injections at home.	To explore how children with RDs and parents experience long-term needle injections at home To explore children's and parents' use of coping strategies at home	Parents are unprepared to handle the injections at home after one training session, technically and emotionally. s Children want to focus on something other than the injections and participate in their regular activities. The side effects of medical treatment are an additional burden. Children want to experience the effects of the treatment to continue with needle injections. Cooperation and shared decision-making within the family are important. The children appreciated the use of coping strategies.
III	Home administration of needle injections for children with rheumatic diseases: A qualitative study on nurses' perceptions of their educational role	To explore nurses' perceptions of their educational role, pedagogical competence, and practicing in teaching children with RDs and their parents to manage treatment based on subcutaneous injections at home	Administering needle injections to children and providing patient education are mandatory tasks for nurses. Nurses perceive their educational role as undefined and their own competence as deficient. Nurses lack sufficient time and organizational support to provide patient education.

6.1 Sub-Study I

"Children's fear of needle injections: A qualitative study of training sessions for children with rheumatic diseases before home administration"

The purpose of the training session for the child and the parents was to receive the first subcutaneous injection to treat RDs, and to be given training for handling these injections at home. The video observations revealed four themes regarding this multifaceted procedure: *children's expression of pain and fear, children's efforts to become involved, adult actions providing children's confidence,* and *adult actions providing children's distress.* Further summarizing of these themes resulted in two additional themes: *children's expression of emotions* and *adults' responses to children's pain and fear.*

Children's expression of emotions

Most children in this study experienced the pain intensity of the needle stick being lower than expected, but an anticipatory fear of pain was present in nearly all participants. Several expressed that they wished they had been prepared for the stinging pain after the injection, which was reported to be more bothersome than the needle stick itself. The nurses did not assess pain and fear systematically, although the children could have reported their pain and fear directly using an age-appropriate tool. The children often expressed their fear indirectly as cues and nonverbal signs, but these were not always perceived by the nurses. All children tried to become involved in the procedure by, for example, asking questions, suggesting coping strategies, or showing engagement when playing with the equipment. This was interpreted as a positive emotional expression.

Adults' responses to children's pain and fear

The child's response to the nurses' type of communication was an important finding in this study, as the communication either supported the child's confidence or increased their distress. Table 9 illustrates the three types: *acknowledging, ambiguous,* or *disregarding communication*. Coping strategies were frequently offered in an unclear way or without sufficient time for the child to understand that these measures could help them during the procedure.

Table 9: *Examples of Different Types of Communication and Responses*

Nurses' Communication type	**Nurses' Quotations**	**Child's Quotation (Behavior)**	**Child Responses (After the Injection)**
Acknowledging	*"It might hurt, right?"* *"You may squeeze your mother's hand?"*	*"Yes" (nods)* *"Then it might not hurt so much."*	Becoming engaged Showing confidence
Ambiguous	*"I do understand if you worry, it might hurt."* *"You do as you like, what you think is best."*	Silent, insecure smile *"I don't know."* Silent cry	Surrendering Showing relief and embarrassment
Disregarding	*"You will hardly notice it."* *"It will be over soon."* *"It doesn't really hurt."*	*"The needle stick will hurt."* *"Yes, but I don't dare"* *"I don't want to."* Cry	Protesting Showing sadness and distress

The structure and technical instructions that defined the contexts for the actions and interactions were characterized by coincidences and lack of adapted equipment and rooms. The nurses had to improvise and collect the necessary equipment and bring it to the child's bedroom.

6.2 Sub-Study II

"I don't want to think about it: a qualitative study of children (6–18 years) with rheumatic diseases and parents' experiences with regular needle injections at home"

In this study, we identified three main themes: *challenges, motivational factors,* and *routines*, and we captured experiences and strategies that influenced the continuation of needle injections at home. As we included participants with both relatively short-term and long-term experience in the individual interviews, the findings reflect a wide spectrum of experiences.

The *challenges* were associated with physical pain and emotional distress related to the injection and other painful procedures. Those with long-term experiences mixed their narratives with procedures for blood samples, joint injections, and peripheral vein cannulations. Most children tried to focus on something other than the needle injections, and although they did not report much pain, some still feared the moment just before the stick.

Most families took various precautions to prevent nausea and vomiting, which are common side effects. Many children described the need for some extra sleep and rest and adjustment of food and activities on the day of and the day after the injection. The parents were concerned about the huge responsibility of handling the treatment for their child at home and did not feel competent after only one training session. Some parents also reported that they had used force to complete the injections when their child was younger and that they lacked knowledge about alternative measures.

The *motivational factors* to continue the injection-based treatment was, foremost, improvement in their symptoms and function. The adolescents clearly stated that they would refuse injection treatment if it had no effect; however, the parents also relied on the results from blood tests and X-rays to show disease improvement. Some parents reported that detailed preparation, predictability, and shared decision-making had improved their child's self-confidence. Children and parents described a common desire to implement injections as a natural part of their daily lives.

An important finding was that all families had built *routines* that were fixed and repetitive, often as organized teamwork, which had a positive influence on their everyday lives. The participants had all used several pain-relieving strategies, but no children recalled any specific instructions from HPs in the use of nonpharmacological measures. Although they were familiar with the use of topical anesthesia, only a few children in this study found this useful or necessary. The parents used prior experiences or searched on the internet for information, but they often discovered useful coping strategies by chance. Parents believed that giving the child knowledge and gradually increasing responsibility gave the child better control and self-confidence.

6.3 Sub-Study III

"Home administration of needle injections for children with rheumatic diseases: A qualitative study on nurses' perception of their educational role"

The analysis of focus groups with nurses revealed three themes: *myriad expectations, awareness of own competence,* and *facilitation and prioritization of patient education*.

Nurses felt *expectations* from their colleagues, leaders, and themselves that patient education was a mandatory duty in their daily work. The nurses were supposed to complete the first injection and give technical instructions to the parents and children before leaving home. The nurses also expected themselves to manage the children's pain and fear and to comfort anxious parents, even though the time to build a relationship was short.

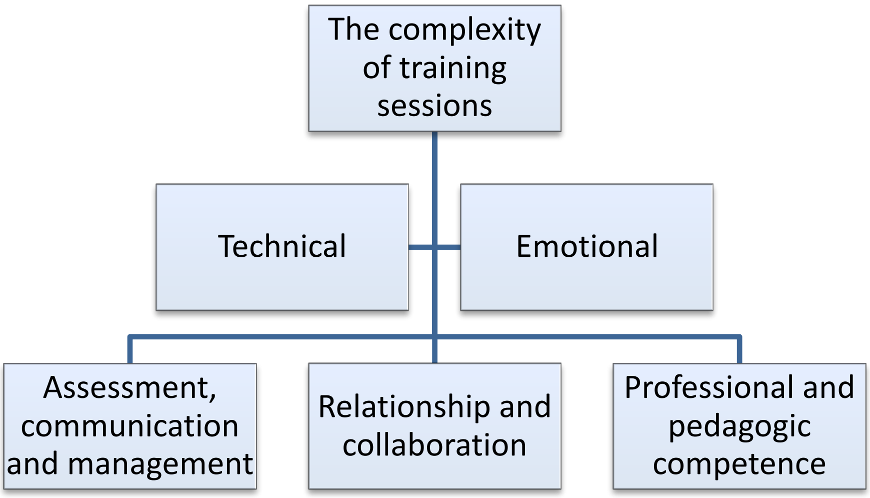
The nurses lacked pedagogical *competence* but struggled to elaborate on what such competence would require. Competence was related to experience adapted in clinical practice rather than skills developed through education. However, the pediatric nurses admitted that they had a broader knowledge of children's development and needs due to their specialization. All nurses lacked guidelines for the purpose, time for reflection within their daily work, and the confidence to use evidence-based measures to comfort children and parents.

Each nurse had the responsibility of *facilitating* patient education as much as possible. The nurses at the ward lacked a specific room equipped for the purpose and had to *prioritize* patient education between other nursing tasks. However, the short-term hospitalization challenged nurses' delivery of extensive patient education during their stay in a pediatric ward. Nurses at outpatient clinics worked more independently and had the opportunity to arrange follow-ups when needed.

6.4 A Holistic Understanding of the Main Findings across the Sub-Studies

This section presents a holistic understanding of the main findings of the study across the sub-studies, as illustrated in Figure 3. The four summarized findings that will be further elaborated and discussed in Chapter 7 are *the technical and emotional complexity of the training sessions; the assessment, communication, and management of children's pain and fear; aspects of relationships and collaboration in hospitals and at home; and nurses' professional and pedagogical competence.*

Figure 3: *Illustration of Holistic Findings across the Sub-Studies*



7. Discussion of Main Findings

The overall aim of this study was to provide new knowledge on how injection training for children with RDs and their parents takes place and how pain and fear are communicated and managed during the first medical injection. Furthermore, we aimed to reveal what children and parents need to help them take care of the injections at home and the prerequisites and competence nurses need to perform the training sessions. In this chapter, I discuss the following summarized understandings of the main findings across the sub-studies: *the technical and emotional complexity of the training sessions; the assessment, communication, and management of children's pain and fear; aspects of relationships and collaboration in hospitals and at home; and nurses' professional and pedagogical competence.* I refer to the different sub-studies by showing the number of the sub-study or sub-studies in parentheses (e.g., (I) or (I, III)).

7.1 The Technical and Emotional Complexity of the Training Sessions

This study showed that administering the first medical injection to a child and providing practical knowledge and skills in handling needle injections is a complex but mandatory task for nurses (I, II, III). Both the nurses at the hospital and the children and parents at home experience several challenges, ranging from handling equipment and medications, and managing children's pain, fears, and side effects, to providing the most suitable environment. Nurses and parents often paid more attention to the technical tasks rather than focusing on the children's emotional needs.

The equipment used for the injections in this study was a major stress factor and required a lot of attention from children, parents, and nurses (I, II, III). The medication doses adapted for children are often smaller than those provided in the prefilled pens or syringes. Thus, the exact dose must be refilled in another syringe. As far as we have been able to trace, there is little research and development of equipment that suits children with RDs. A recent Polish study, however, showed that children ranked pens as easier to use than syringes and that the level of pain and side effects was significantly lower (Roszkiewicz et al., 2020). A possible bias in this study was that all the participants (n = 23) had used syringes before the introduction of the pens, and the novelty of pens might partly explain the effect. Our findings showed individual preferences for whether the children favored syringes or pens (II), although some nurses stated that pens appear less painful than syringes (I). As long as not all possible injection devices are available for children, our findings emphasize the importance of providing children with sufficient time to become familiar with the equipment they will be using at home (I, II, III).

At the onset of this study, injection-related pain and fear in children with RDs were not sufficiently studied (Bechard et al., 2014; Mulligan et al., 2013; van der Meer et al., 2007). A recent literature review showed that previous studies had included only children receiving MTX, and that studies of injection-related distress in children receiving biologics were lacking (Jacobse et al., 2019). The side effects of MTX have been shown to be a reinforcing factor in pain and discomfort, and the incidence of intolerance is shown to be even higher among children with JIA compared to children with lymphoblastic leukemia (Kyvsgaard et al., 2019). Most children in the present study used MTX in addition to biologics (e.g., etanercept or adalimumab) (I, II), which made it difficult to separate the side effects of each drug. The children reported feeling tired and taking precautions to prevent nausea by using weekends for medication (II). Side effects, pain, and embarrassment related to the treatment have been shown to be important barriers to adherence in children with RDs (Favier et al., 2018), and drug administration on weekends can further represent a burden on young people's social lives. A study on Irish adolescents emphasized the need for social support to manage their condition independently (O'Sullivan et al., 2018). The findings in the present study suggest that HPs struggle to prevent and treat side effects that interfere with children's and adolescents' daily lives (II). Aiming to improve the control of side effects of MTX, a Dutch interdisciplinary research group plans to investigate the effects of psychobiological principles of pharmacological conditioning (Smits et al., 2020).

Parents and nurses in this study were aware that bad memories of painful procedures could affect future experiences (II, III). One example was a child who had been physically restrained during previous blood tests and now refused the recommended injection-based treatment. The development of procedural pain and fear is complex, and children's reluctance may lead to adult's use of holding and restraint, which may, in turn, lead to bad memories. Researchers have gradually become more concerned with this phenomenon (Pavlova et al., 2020), and negatively biased recall of pain has been shown to increase anxiety and tendencies to catastrophize about pain in later painful procedures (Noel et al., 2019). It is possible to reframe memories; however, nurses must teach parents to reminisce about painful memories with the child in a way that does not reinforce negative experiences (Pavlova et al., 2020). The present study showed that nurses often lack the competence and time to provide measures that create a positive experience in a hectic hospital setting, even though they are aware of the connection between bad memories and future experiences of pain. Nurses at the outpatient clinics had better prerequisites and settings, and gave examples of how they could turn children’s previous bad experiences toward increased coping by offering the child a fresh start (III).

The nurses who worked in the ward lacked suitable rooms and had limited time for the training sessions (I, III). They even had to bring the necessary equipment to the child’s bedroom. By contrast, the nurses working at the outpatient clinics had suitable rooms and more available time for the implementation. Traditionally, rooms at hospitals are designed to facilitate HPs’ needs and focus on the child’s safety during the procedure, with a monitor, bright lights, and so on; however, appropriate surroundings are essential for minimizing children’s pain and distress (Leroy et al., 2016). Research in this area is limited, but children seem to prefer new facilities decorated with colorful walls and pictures, toys, and games that are available for distraction, as they reduce children’s anxiety (Pauli Bock et al., 2021; Kleye et al., 2020). At home, the families in this study had arranged firm routines with a fixed place to perform the injections, which they experienced as stress-reducing (II). Specially equipped rooms at the ward would help the nurses, children, and parents save time and reduce stress for all parties.

7.2 Assessment, Communication, and Management of Children’s Pain and Fear

The findings showed a lack of systematic assessment of children’s pain and fear, and identified three types of communication affecting the completion of the training session (I). Many parents were unprepared to handle the injections at home after one training session (II), and coping strategies were used randomly, both at hospital and at home (I, II, III).

7.2.1 Assessment of pain and fear

Although nearly all children worried about injection pain, the nurses did not systematically assess pain and fear (I, III). The children continued to fear the needle stick at home, even though they felt little pain (I, II). This was not a surprising finding, as needle fear is common in both preventive care and among children undergoing medical treatment (McLenon & Rogers, 2018; McMurtry et al., 2015; Taddio et al., 2012). Previous research has highlighted the importance of assessing children's and parents' needs to provide a foundation for an empowering education (Kelo et al., 2013). Recognizing a child's pain and fear should be part of such an assessment, followed by an empathic response, such as communication about the child's emotions (Peplau, 1997). Interpersonal constructs may also be communicated by the physical body (Peplau, 1952), and crying may be an appropriate coping response if the child has not been prepared or understands what is going on. Therefore, expressed negative emotions should be recognized as a tool to regulate children's emotions and not suppress them (Havik, 1989; Lazarus, 2006).

By introducing the term *resembling* in the revised definition of pain in 2020, IASP has stated that verbal description is only one of several behaviors used to express pain: "Pain is an unpleasant sensory and emotional experience associated with, or *resembling that associated* with, actual or potential tissue damage" (Raja et al., 2020). The revision to the definition of pain is important, but the implementation of evidence-based pediatric pain management does not yet appear to be complete in clinical practice (Eccleston et al., 2021; Jordan et al., 2021). Evidence-based pediatric pain management must include a systematic assessment of children's pain and fear by asking those who are able to self-report, and use age- and developmental-appropriate tools for nonverbal children (Manworren & Stinson, 2016; McMurtry et al., 2011). All children in this study were old enough to be able to rate their pain and fear on a scale from 0 to 10; however, the nurses did not ask them (I). The investigation of the video recordings identified several cues on fear that had remained undetected in real life because such cues appear as small variations that are hard to detect. A recent Swedish study also showed similar results that children rarely were asked to self-report pain and fear, or observed using an assessment tool before needle procedures (Karlsson et al., 2021). Research has shown that the level of needle-related fear among children can be as intense as the experience of pain (Heden et al., 2020). The fear of needle-pain was also evident in the present study, and was, notably, present at home long after they had become accustomed to the injections (II). Distinguishing between a child's experience of pain and fear may be important when choosing the most appropriate coping strategy (Heden et al., 2016; McMurtry et al., 2011), and it is possible to measure pain-related fear using tools similar to those used for measuring pain intensity (Ersig et al., 2013; McMurtry et al., 2011). It has been shown that children (aged 7–18 years) with type 1 diabetes, who report higher pain scores during needle procedures, have a poorer coping ability and need additional support from pediatric diabetes teams to develop sufficient coping strategies (Hanberger et al., 2021). Nurses have a central role in assessing children's fears, to act from a child's perspective (Nilsson et al., 2015; Söderbäck et al., 2011) and to safeguard children's right to express their views (United Nations Human Rights, 1989). Assessing the levels of pain and fear is often the first step in providing sufficient management and preventing progression into needle phobia (Orenius et al., 2018).

7.2.2 Types of communication

A key finding of this study was how the type of communication affected the training and implementation of the first injection (I). The children wanted to be involved in the decision-making process, and when the nurses used an acknowledging communication type and addressed the children's pain and fear, a collaborative process began (I). Children's positive involvement was also present at home (II). A previous qualitative study of children (aged 3–7 years) showed that children's involvement requires that nurses' guidance be based on the child's reactions (Karlsson et al., 2016). Children want to have an influence, make decisions about their need for information, and know how to deal with pain and fear, but they also want to think positively, behave bravely, and have control (Kleye et al., 2020; Quaye et al., 2019). The present study showed that nurses often talked about the technical aspects of the procedure instead of responding to the child's emotional concerns, and thus failed to decrease the child's fear (I). To become better at providing information and support to young people, a recent systematic review showed that HPs need to practice and acquire communication skills and involve children in decision-making processes (Jordan et al., 2018). This finding is in line with research that emphasizes the need for HPs to learn to respond to the patient's cues, as emotional concerns are more likely to be presented as cues rather than clear concerns (Piccolo et al., 2017; Vatne et al., 2012; Zimmermann et al., 2011).

Peplau (1952) stated that nurses' communication might even have therapeutic effects that promote the patient's long-term well-being. However, such communication requires attentive listening and the use of an understandable language; therefore, communication skills should be part of the nurse's repertoire; otherwise, there is a danger that nurses will fall into a kind of "social talk" (Gastmans, 1998; Simpson, 1991). Providing person-centered communication with children may also encompass the use of alternative communication strategies, such as images and digital apps (Thunberg et al., 2021). Research in this field is currently sparse, but the effect of applying digital apps for assessing and managing the symptoms of children with various persistent conditions is under development (Thunberg et al., 2021). The consequences of failed communication can cause the patient to lose dignity and respect and to show resistance, which prevents the relationship from growing (Peplau, 1952). Interpersonal theory may assist nurses in observing more intelligently and intervening more sensitively than without this knowledge. In this way, Peplau's (1952) concepts of interpersonal processes still give substance to the concepts of self-management and shared decision-making (D'Antonio et al., 2014; O'Toole & Welt, 1989).

7.2.3 The use of coping strategies

We found that coping strategies were used randomly at the hospital and at home, which corresponds with the findings that nurses lacked the competence to convey these strategies to children and parents (I, II, III). To promote and guide clinical practice in managing needle-related pain, research recommends combining pharmacological and psychological interventions (Blount et al., 2006; Flowers & Birnie, 2015). Several interventions have been shown to be effective for this purpose (Birnie, Noel, et al., 2018; Loeffen et al., 2020; McNair et al., 2019), as described in Section 2.3.3. With the historical perspective in mind, it is important to remember the need for access to pharmacological measures, although procedural pain can often be managed using nonpharmacological techniques, good preparation, and involvement of the child. The only pharmacological measure children in the present study had been offered was topical anesthetics, although most of them managed without (I, II, III). Nitrous oxide is available at many pediatric wards and outpatient clinics in Norway and, when needed, is recommended as a first-choice pharmacological alternative during painful minor procedures (Pedersen et al., 2013). Nitrous oxide might be adequate to ease bad needle-related experiences, but it is not available for home treatment.

In this study, mobile phones were the most frequently used nonpharmacological measure for distraction, both at home and at the hospital (I, II, III). Mobile phones, computer tablets, and virtual reality are popular among children and are easy to use. Studies have shown that digital distractions are safe and acceptable and provide a small but clinically important reduction in children's experiences of pain (Birnie, Kulandaivelu, et al., 2018; Gates et al., 2020). However, their superiority over non-digital distractors has not yet been established (Gates et al., 2020; Lambert et al., 2020). Attention to the child's preferences is advice that remains important (Gates et al., 2020; Koller & Goldman, 2012; Lambert et al., 2020). Sometimes, nurses are unable to decrease the child's fear by suggesting coping strategies. Our findings showed that taking a break might help the child regain self-control and confidence if the fear escalates during a procedure (I, III). These breaks have similarities with the term "clinical pause," which gives the nurse an opportunity to rebuild a relationship with the child and explore alternative approaches to cooperation without restraint (Bray, Ford, et al., 2019; Svendsen & Bjørk, 2021).

Neither children nor parents remembered that they had received information or training in the use of coping strategies (II). Parents had strived to find information about coping strategies and lacked guidance on how they should support their child emotionally (II). Research shows that if parents receive guidance from nurses, their coping promoting behavior will have a great impact on children's coping in painful procedures (Campbell-Yeo et al., 2017). If not, they may act as gatekeepers and impede children's access, understanding, and use of procedural information (Bray et al., 2019a). Therefore, nurses should encourage and empower parents to be involved in different coping promoting strategies and teach parents how to avoid distress-promoting behaviors (Campbell-Yeo et al., 2017). However, the nurses in this study lacked the necessary education to promote the effective management of procedural pain and fear (Loeffen et al., 2020). Furthermore, the findings in this study confirm the recurring problem of conveying evidence-based pediatric pain management into clinical practice (Eccleston et al., 2021; Jordan et al., 2021).

In recent years, social media has provided new opportunities to bring health information directly to parents and HPs. Researchers in Canada and the United States have utilized the opportunity to share evidence-based information with parents on how they can help their children through painful procedures. This KT has been specially adapted for vaccinations, which is of great importance, as it is the most common needle procedure among healthy children (Gates et al., 2018; Higgins et al., 2021). Both parents and HPs have found the campaign on YouTube, called "It Doesn't Have to Hurt", easy to understand and helpful in supporting children during needle procedures (Chambers et al., 2020). Although the advice may not be applicable to every setting, e.g., emergency procedures (Gates et al., 2018), the main message is likely to be transferred into different contexts. Developments in technology have made it possible for parents to take advantage of tools that provide an individual assessment of children's risk of distress from needle injections and instructions for distraction. The Distraction in Action Tool (DAT) showed promising results when tested on a small sample of children (aged 4–10 years), parents, and clinicians in an emergency department and a phlebotomy lab (Hanrahan et al., 2017). However, it remains to be seen whether such a tool could also be useful for children in various settings, such as in chronic conditions like RDs.

7.3 Aspects of Relationships and Collaboration

The current context of short hospital stays requires an immediate establishment of relationships with a focus on children's and parents' needs to manage treatment at home (I, II, III). However, the nurses in the present study felt that they lacked time for procedural preparation and that the information they needed to convey to those involved was comprehensive (I, III). Sub-study I showed how the type of communication influenced the collaboration between the nurse, child, and parents. Pre-procedural preparation includes giving children sensory and procedural information to gain the best possible understanding of what is going to happen (Bray et al., 2019b; Cohen, 2008). Although procedural information and preparation are important, these alone do not reduce children's pain or distress, nor do they suggest that the procedure is doing well for the child (Birnie, Noel, et al., 2018). Research and clinical projects highlight children's autonomy and place increasing emphasis on how providing a child-centered focus during painful procedures empowers children and parents (Bray et al., 2019a; Loeffen et al., 2020). The Comfort, Ask, Relax, Distract (CARD) system is an example of a project that combines patient empowerment with education for both HPs and patients (Taddio et al., 2019). Such a practice is in line with Peplau's (1952) view that the patient should be active participants and share experiences and mutuality in the relationship with the nurse, instead of a practice where patients receive treatment passively.

The routines and collaboration within the families were important for strengthening the children's ability to cope with injections at home (II). This finding is in line with the view of coping as a relational process, where emotions depend on what transpires between a person and the environment (Lazarus, 2006). The foundation of relationships usually builds on trust between patients and HPs and is often taken for granted without being explicitly communicated (Skirbekk, 2009). Trust is usually implicitly negotiated through discussions on harmless topics or activities. The routines and collaboration in the families were based on a mutual trust between the child and parents, which is essential for decreasing needle-related distress (II). In several families, the children gradually gained increasing responsibility for the injections, which was likely an important factor in maintaining a trusting relationship.

The procedure of administering medical injections to children with RDs has the potential to be perceived differently from different viewpoints. From the child's perspective, the experience of the injection is not necessarily useful unless the child understands the intention of symptom relief (I, II). However, research has demonstrated that most HPs would use physical restraint if a child became uncooperative during such a procedure, justified by acting in the best interests of the child (Bray et al., 2019). The concept of "transient empathic blindness" can describe what happens in HPs' brains when using forceful restraint to children (Loeffen et al., 2020). In the present study, no adults used physical restraint to complete the child's first injection (I); however, nurses and parents shared such experiences from previous procedures (II, III). The use of physical restraint creates a negative relationship between the child and the nurse (and parent) and undermines the child's rights (United Nations Human Rights, 1989). Nurses may feel moral distress but justify the choice by the necessity of the medical treatment (Bray et al., 2019; Svendsen & Bjørk, 2021). The ethical principles of beneficence, autonomy, and non-maleficence challenge whether nurses lack alternatives to restraint (Beauchamp & Childress, 2019). Peplau (1952) emphasized the nurse–client relationship as a foundation of nursing practice and encouraged nurses to reflect on their attitudes and actions (D'Antonio et al., 2014). Reflection is an important counterweight to be drawn into emphatic blindness.

In sub-study I, we observed how parents followed the nurse's guidance in the training session and acted more comfortably when the nurse took the leadership role. Parents confirmed this finding in the interviews and said that they had more confidence in nurses who showed self-confidence. Sometimes, they wished the nurse should have taken more control over the training session (II). These findings are in line with a review describing how parents often believe HPs expect them to do the comforting of their child, while parents often want the HPs to take the leading role (Gates et al., 2018). Research has shown that parents' behavior and talk have a great impact on how children react and cope with painful procedures and can worsen children's distress (Brown et al., 2018; Racine et al., 2016). A recent systematic review emphasized that if the parents apologize, give the child too much control, empathy, or criticism, the child's distress and pain increases during medical procedures (Sobol-Kwapińska et al., 2020). Being aware of the leadership role may be essential for nurses; however, this requires sufficient professional and pedagogical competence.

7.4 Nurses' Professional and Pedagogical Competence

Administration of injections is basic knowledge for nurses, but requires greater attention when the patient is a child, is afraid, and is receiving a needle injection for the very first time. The present study revealed that nurses often felt squeezed between the many nursing tasks, as well as describing uncertainty about their own competence and pedagogical role (III). Peplau's (1952) theoretical perspective of the three phases in nursing provides an understanding of the impossibility for nurses to complete these phases in one short training session. The child and parents need time to become cognitive and emotionally mature, and skills to handle their disease and treatment (Kelo et al., 2013), which requires a stepwise approach. If the nurse is to act from the child's perspective and encourage participation in all types of decisions, this will require organizational, social, pediatric, and pedagogical competence (Quaye et al., 2019). To become a nurse who fulfills the role of resource person and counselor, it is necessary to take advantage of current evidence-based care.

The nurses in the present study lacked sufficient professional competence in pain management (I, III). Improving pain management requires a multifactorial approach, including education, decision-making strategies, and organizational practices (Twycross, 2010). However, clinical practice still fails to provide sufficient pain relief for children, and a recent review from the Lancet Child & Adolescent Health Commission emphasizes that pediatric pain management needs prioritization to be improved (Eccleston et al., 2021). The report highlights that pain education for HPs remains inadequate, that there is a lack of investment in research and services, and that access to pain management is unequal. One recurring problem is KT, and evidence-based clinical guidelines are rarely used to manage pain in children (Birnie, Chambers, et al., 2014). One of the largest children's hospitals in the US has implemented a system-wide intervention they called "Children's Comfort Promise," which is a promise to do everything to prevent and treat pain. They put forward four simple pieces of evidence-based advice as "non-negotiables": (1) Numb the skin using topical anesthesia; (2) administer sucrose or breastfeeding for infants < one year; (3) do not hold the child down—children want to sit on their parent's lap—and restraint is never supportive; 4) use age-appropriate distraction. This project resulted in decreased needle pain caused by vaccinations, blood draws, intravenous access, and injections (Friedrichsdorf et al., 2018). The combination of pharmacological and psychological measures is well-known advice, but one factor for the success may be that pain management was made an organizational priority and that all HPs had to commit to these four measures—every time (Friedrichsdorf et al., 2018). The nurses in the present study lacked guidelines and knowledge of advice for "standard care," as described in the project above (I, II). There is an ongoing need to develop and adjust guidelines to suit different patient groups and contexts (Blount et al., 2006).

The goal for the training sessions was to provide the first injection to the child, and to teach the child and parent practical knowledge and skills (I, II, III). An overarching goal, however, is to provide these children and parents with the necessary health literacy to take care of injection-based treatment and improve their self-management. The Norwegian "Strategy for improving health literacy" mentions briefly that parents' health literacy is important to make appropriate health choices for their children, but has no suggestions to act directly toward children (HOD, 2019). How to identify children's health literacy has not yet been clearly stated (Bröder et al., 2019); however, the need to add *patient activation* to the concept of *health literacy* is emphasized (Yadav et al., 2019). This means that to promote self-management, motivation and the ability to act are necessary factors in addition to skills and self-confidence. For children with different chronic diagnoses, educational interventions must be tailored to the child's age and developmental stage to improve self-management, including skills, attitudes, and behaviors (Saxby et al., 2019). Studies of children with RDs have investigated self-management needs (Connelly et al., 2019; O'Sullivan et al., 2018), children's overall experience with care (van Dijkhuizen et al., 2018), barriers to treatment adherence (Favier et al., 2018), and the use of shared decision-making aids (El Miedany et al., 2019) to provide better treatment outcomes. These studies confirm the need for improved care and education for children with RDs. A recent international cross-sectional study examined aspects of children's health literacy related to the information needs and understanding of COVID-19 (Bray et al., 2021). More attention to children and parents' health literacy and an individual facilitation of teaching may increase their ability to manage the treatment at home (Bröder et al., 2019).

The nurses in the present study struggled to elaborate on what pedagogical competence meant and why they needed such competence (III). Viewing the nursing role from a health-promoting perspective, the role of educator should be as important as caring for critically ill patients (Gastmans, 1998). However, to fulfill the role of educator, nurses need comprehensive competence in nursing, didactics, and skills to develop and empower a child-centered education (Kelo et al., 2013; Peplau, 1952). Effective patient education should include structured curricula, active participation, collaboration, autonomy, feedback, multiple exposures, and problem solving (Saxby et al., 2019). Nurses' competency in pedagogy should be more visible, supported by managers, and preferably possible to assess in the future (Bergh et al., 2014; Hwang et al., 2018). As concluded in sub-study II, perhaps not all nurses should provide extensive patient education for children with RDs and their families, and should instead leave follow-up and education to specialized nurses at outpatient clinics. A notable finding across the sub-studies was that the information and support from the user organization (BURG) and professional organizations (e.g., NAKBUR, PRINTO) are not fully utilized as resources for children, parents, or nurses. International research has increasingly used web-based solutions to provide children with peer support and has investigated the effect of self-management programs (Connelly et al., 2019; Stinson et al., 2016; Stinson et al., 2020). The results from these studies have shown significant reductions in pain and improved HRQL among young people with JIA. The website AboutKidsHealth for Teens is an example that contains several learning hubs; for example, the CARD system helps manage pain and fear during vaccination. In the future, web-based solutions for patient education will provide an advantage for families, especially for those living far away from hospitals.

8. Methodological Considerations

There is no absolute consensus on how to judge the quality of qualitative research (Rolfe, 2006), but the principles of transparency and reflexivity are regarded as essential in all qualitative research throughout the process (Green & Thorogood, 2018; Moen & Middelthon, 2015). Qualitative research should be founded as a systematic and reflective process and should develop knowledge with the ambition of transferability beyond the study setting (Malterud, 2001). Improved reporting of quality is one way to empower readers to critically evaluate qualitative studies and apply and synthesize results. Therefore, checklists and standards, such as the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) and the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014), are commonly recommended to guide the authors of qualitative studies. We used COREQ to guide the report of sub-studies I and II, and SRQR to guide sub-study III in accordance with the journals' preferences. However, Malterud (2001) introduced the concepts of *relevance, validity,* and *reflexivity* as overall standards in qualitative research, instead of relying on checklists. Reflexivity is an ongoing process in qualitative research that includes questioning the findings and interpretations, assessing their validity, evaluating the impact of context and bias, and discussing the analytical process (Malterud, 2001). To make the research process logical, traceable, and clearly documented, I have kept a reflexive research audit (Nowell et al., 2017; Rolfe, 2006), which includes a diary (five notebooks) that shows the steps taken and the many ideas and questions that emerged throughout the study. The records of raw data, field notes, transcripts, and the reflective diary were useful in reporting the research process. The construction of this chapter includes considerations regarding the researcher's influence on the study, the relevance and validity of the study, the principles and significance of sampling, and the interpretation during analysis (Malterud, 2001). Furthermore, I highlight some ethical considerations of including children in research.

8.1 My Position as a Researcher in the Field

The researcher needs a reflective approach to assess their own position and relationship to the field (Green & Thorogood, 2018). It was challenging to master the balance between being close enough to understand the phenomenon I was investigating and keeping a certain distance to clarify patterns that could be taken for granted (Moen & Middelthon, 2015). My clinical experience with pain in children as a specialist nurse at a pediatric intensive care unit and pain clinic was valuable in identifying knowledge gaps and focus for the study. However, this strength also represented a limitation, as my pre-understanding of procedural pain and fear in children was potentially biased. Therefore, I asked several nurses and physicians at different pediatric wards and outpatient clinics about their clinical challenges with procedural pain in children before planning the study. My clinical background gave me easy access to the research field, and I felt comfortable communicating with the children and parents. However, my experience as a researcher was limited to individual interviews with children for my master's thesis. Therefore, I prepared by reading research literature and talking to senior researchers, experts in video research, and specialist nurses working with children with RDs. When my role changed from a clinical nurse to a researcher, I made it clear to the participants that I would keep this role during the study period.

During participant observation, the researcher becomes part of the interaction and the context that is investigated (Moen & Middelthon, 2015). Rather than claiming objectivity, accepting biases, subjective impressions, and partial narratives are inevitably part of the research process. In addition to placing video cameras in the room during the training sessions, I chose to be present, which could further amplify my influence on the participants' actions and interactions (Heath et al., 2010). The children's rooms had limited space, and although I withdrew to a corner, I sometimes felt uncomfortably close to the participants during the procedure. This proximity challenged my role as a researcher, but I remained an observer without participating in the clinical procedure. Nevertheless, being present provided me with valuable information that cannot always be recorded, such as the atmosphere or the actions outside of the camera's window. I was also able to change the cameras' positions or turn them off if one of the participants suddenly changed their minds about participating. It was never necessary to stop the recordings, but twice, the participants moved outside of the camera's window. The first time this happened was in a very relaxed atmosphere, and I chose to move one of the cameras to another position without disturbing the interaction. The second time, however, the child was very afraid, and the nurse tried to persuade the child to accept the injection. At that time, the atmosphere was too tense to relocate the cameras as the action would have disturbed the interaction too much. However, being present, I could still observe the facial expressions and continue to record the sounds. An additional benefit of being present was natural access to a quick interview immediately after the procedure was completed. The participants claimed that they very soon stopped thinking about the recording, but my experience was that their attention to the cameras and my presence varied throughout the procedure. The nurses said that they performed the procedure ‘as usual’, which meant that they did their very best and that the video recording did not negatively affect their behavior. However, they also admitted that they had been nervous beforehand, which may have negatively affected their approach to the child.

When I met the children and parents for individual interviews later, we had already established a relationship during sub-study I, and my experience was that they were eager to share their stories. Although I was clear about my role as a researcher, they may have perceived me as a representative from the hospital and failed to share with me their bad experiences with HPs. My position in the focus groups was different, as none of the participants or researchers had met before, so we had to build a relationship in a very short time.

8.2 The Relevance and Validity of the Study

The design of the original project plan included an intervention study aimed at testing the effect of implementing CPG to minimize the pain and fear associated with injection-based treatment among children with RDs. However, several reasons made this idea difficult to implement. First, we could not find descriptions of how injection training for these children takes place or how they experience and express pain and fear in such situations. These knowledge gaps seemed necessary to address by conducting an exploratory qualitative study to gain in-depth knowledge about the phenomenon of interest, and possibly generate a hypothesis for a later quantitative intervention study (Creswell, 2014). Second, important obstacles to conducting an intervention study were the lack of suitable questionnaires for children translated into Norwegian, the definition of adequate outcome measures, and the recruitment of a sufficient sample size within the timespan of a Ph.D. study. It became clear that there was a need to explore the participants’ perceptions, the prerequisites for patient education, and the participants’ needs. The video observations and individual interviews were planned from the beginning. However, to conduct a thorough exploration, we decided to include children and parents with long-term experience of injection-based treatment, as well as experienced nurses’ perceptions of patient education in this context. Reflecting on these choices, the decision to leave the planned intervention study seems right. Pain and fear in children with RDs were not sufficiently explored to determine the most appropriate design for an intervention study; furthermore, the time a Ph.D. student had available was a limiting factor.

The concepts of reliability and validity lack a consistent definition in qualitative research (Green & Thorogood, 2018). Validity is socially situated, and instead of describing validity as the "truth," considerations about validity are an ongoing process often linked to the concept of *trustworthiness*. Trustworthiness refers to the extent to which the reader can be confident in the implementation of the research and the rationale for the conclusions drawn (Green & Thorogood, 2018; Malterud, 2001; Rolfe, 2006). Several criteria provide trustworthiness in qualitative research (Green & Thorogood, 2018; O'Brien et al., 2014). For example, the use of multiple sources for data generation, providing rich contextual information and information about the analytical steps, as well as the availability and organization of the data, as shown in Chapter 5. Accounting for similarities and differences across cases, are another criteria of trustworthiness, which are exemplified in the articles and discussion of findings in Chapter 7. Member checking is also a commonly used criterion for providing trustworthiness that is included in the COREQ checklist (Nowell et al., 2017; Tong et al., 2007). However, because the aim of getting the researchers and the participants to perceive the results in the same way is unlikely to happen, member checking is not viewed as the gold standard in qualitative research (Green & Thorogood, 2018; Rolfe, 2006). However, member checking might strengthen trustworthiness in certain areas. For example, in this study, we asked the children to self-report their experiences of pain and fear immediately after the training session, which increased the trustworthiness of our interpretation of expressed pain and fear in the video recordings. We also invited a nurse responsible for the professional development in the ward to watch some anonymized clips from the videos. Her interpretation and recognition of certain situations corresponded well with our analysis, which I believe also strengthened the trustworthiness of our findings.

Transferability refers to the generalizability of the findings and contains the variety and limits for the presentation of the findings beyond the context of the study (Malterud, 2001). The assessment of whether the results are transferable is left to the reader by providing thick descriptions of demographics, study setting, and analytical steps. Findings in qualitative research are not intended to be valid for every population group (Malterud, 2001), but the patterns of experiences and actions among children, parents, and nurses may be recognizable to readers and provide a basis for further professional development and research.

8.3 Sampling and Sample Size

This study aimed to understand common perceptions and experiences among a relatively homogeneous sample of children with RDs and their parents and nurses. Therefore, purposive sampling allowed us to choose cases that could illuminate the topics and interactions of interest for the study (Silverman, 2014). The decision on the number of cases needed in qualitative research will vary and depend on the number that is trustworthy to the readers of the research and the reasons for including cases (Green & Thorogood, 2018). The concept of *data saturation* is routed in grounded theory, and means including data until no new findings occur from the analysis and all variations and relationships are accounted for (Green & Thorogood, 2018). Data saturation is considered a credible criterion for providing rigorous data collection. However, deciding when actual saturation is achieved can be both time-consuming and difficult to determine (Green & Thorogood, 2018; Malterud et al., 2016). Data saturation is used in standards for reporting qualitative research (Tong et al., 2007); however, it is criticized for being used as an automatic statement rather than ensuring the quality of a study (Green & Thorogood, 2018; Malterud, 2001; Thorne, 2020b). In this clinical study, we considered the concept of *information power* to be more appropriate for guiding the sample size. Information power means that a study needs fewer participants if the sample can provide rich information for the purpose of the study (Malterud et al., 2016). One of the factors that influences information power is the quality of the interviews. Although my experience as a researcher was limited, I believe that my background and preparation provided a trusting relationship with the participants, which increased the quality of the interactions with the participants. The many deliberations and discussions in the research team, consisting of people with different professional backgrounds, may also have increased the power of information. The aim of this study was limited to exploring the participants' experiences and actions in a uniform procedure (i.e., needle injections), and it therefore required a smaller sample than if the purpose was to investigate, for example, quality of life in general for children with RDs. However, the intention was to include a few more participants in the video observations, which could have strengthened our results, especially regarding the types of communication. Our relatively small sample indicates three types of communication described in sub-study I, but a larger sample may have also revealed other types or added more power to those we defined. Another limitation of this study was that we recruited the sample from one hospital in the southern part of Norway, although some of the participants lived in other parts of the country. We originally intended to include participants from different contexts, but for practical reasons, only nurses from another hospital were included in the sample.

8.4 Interpretation and Analysis

TA was chosen as the main method for the qualitative analysis because of its' flexibility and potential to be applied across different theoretical and epistemological approaches (Braun & Clarke, 2006; Terry et al., 2017). TA provides a systematic approach to identifying, analyzing, and reporting patterns within data, but it may also provide further interpretation of some aspects related to the aim of the study.

The coding in this study was mainly an inductive process, which is a common approach in qualitative analysis (Braun & Clarke, 2006; Terry et al., 2017). Descriptive studies often consider a method by which two people independently code the data to provide reliability (Green & Thorogood, 2018; Tong et al., 2007). However, the researcher's subjectivity is integrated using the inductive approach, and we could not expect two researchers to independently identify the same codes in the dataset (Green & Thorogood, 2018; Rolfe, 2006). The coding and development of themes are interpretative processes that cannot be right or wrong, only stronger or weaker (Terry et al., 2017). The video recordings were resources where we could search for children's expressions of pain and fear, as well as the interaction and communication between participants. To discover important details and nuances in the participants' expressions and interactions, we chose to work as two researchers collaborating on the coding of this material. IA allowed us to study events in the video recordings more closely to understand the complexity of the training sessions (Jordan & Henderson, 1995). By viewing and assessing the videos in collaboration, we agreed on the interpretation of talk and actions and later discussed our understanding with the entire research team. The group sessions were important to clarify details and patterns that could otherwise have been overlooked or taken for granted (Knoblauch & Schnettler, 2012). IA strongly recommended such a method for analyzing video material to ensure trustworthiness (Jordan & Henderson, 1995). Analyzing the video recordings continuously while new sessions were included helped us decide when our material was rich enough to end the data collection.

In this study, we aimed to conduct an in-depth exploration of the themes by completing a reflexive interpretation and deliberation in the research group, seeking to question all common sense and taken-for-granted assumptions (Green & Thorogood, 2018). The analysis includes interpreting the findings in light of previous empirical and theoretical perspectives. We did not pre-define any theoretical framework; however, relevant concepts and theoretical perspectives were included based on the findings of each sub-study. One example was the need to include literature from the field of communication when we identified how types of communication affected children's emotional expressions. Sub-study II actualized the concepts of health literacy and self-management, highly relevant concepts that should probably have been discussed more thoroughly in the article. The findings in sub-study III inspired me to include a theoretical framework within pedagogy and the nurses' pedagogical role. Peplau's (1952) theory of interpersonal relationships in nursing includes concepts such as *communication and self-management*, and emphasizes the *nurse-client relationship* as a basis for a pedagogical and therapeutic nursing practice. Peplau's (1952) theory could probably serve as a foundation for a study design; however, it is notable that a 70-year-old nursing theory is still relevant to the discussion in this study.

The analysis in this study includes an understanding of the participants' experiences and actions within a broader social context, and can therefore be regarded as a contextualist approach (Braun & Clarke, 2006; Terry et al., 2017). This approach is in line with the aim that qualitative research should add value to a field beyond a simple descriptive reporting of the findings, and never legitimate "the themes" as an endpoint of the analysis (Thorne, 2020a). However, conducting in-depth interpretive processes requires practice over time as a researcher. Although my own experience as a researcher was limited, the many discussions and sessions within the research group throughout the process strengthened the validity of the analytic process and the findings presented.

8.5 Ethical Considerations

Traditionally, studies of children's health have been proxy reports from parents, even though they often have different perspectives from the children (Bray et al., 2015; Söderbäck et al., 2011). At the onset of this study, two out of three studies that had investigated injection-related pain and distress in children with RDs were proxy reports from parents (Mulligan et al., 2013; van der Meer et al., 2007). An overriding principle is the right of children to express their views on issues concerning their own health (United Nations Human Rights, 1989), which includes their right to participate in research (Backe-Hansen, 2009; Söderbäck et al., 2011). There are, however, some important ethical issues to consider when including children in research: *power relations, informed consent,* and *confidentiality* (Acker, 2003; Kirk, 2007). An unequal power relation between adults and children exists, and most children listen to their parents' advice. Clinical research has become increasingly common in society, and the parents in our study were exclusively positive about participating, which most likely influenced the child's decision. Although I reassured the children that participation was voluntary, there was a risk that they did not dare to be completely honest. We limited the inclusion criteria to children aged at least five years to ensure that they were able to participate in individual interviews. However, children as young as three years old may be able to tell about their experiences at the hospital (Acker, 2003). Including such young children may have provided valuable data, but it would have required experience in interviewing small children. One child who invited me to play and watch the needle injections instead of talking posed a challenge for me. I was not prepared on this alternative method of communication, which should preferably have been video-recorded in order to analyze the child's actions as well as the verbal talk.

All children appeared more confident in the individual interviews than during the video observations; they welcomed me, their speech was clearer, and they were eager to share their experiences. Any type of field observation is emphasized as important before interviewing children (Acker, 2003), and in a way, one can say that the video observations served as fieldwork in front of the interviews. Enabling the participants to view video recordings of themselves may be a way of member checking. I was insecure about allowing the children to view the video, but tried it out twice. My interpretation of these occasions was that the children were embarrassed and did not want to be reminded of how scared they were during the first injection. I discovered a similar behavior shown in a Swedish study (Karlsson et al., 2016), and in my opinion, this is not a method to use routinely for validating data with minors. To maintain confidentiality, we offered for all children to be alone during the interview, but the two youngest children preferred that their parents be present. Although the parents intended to let the children speak for themselves, it may have influenced the quality of these interviews.

Interviewing children in groups may provide a more natural context that reduces power imbalances (Acker, 2003). In this study, the youngest children appeared to speak more freely in the focus groups than the adolescents who participated. This observation may have been coincidental, but one explanation might be that we had more available time with the youngest children and started the group session with a “get-to-know-each-other” game. The focus group with adolescents took place during a weekend seminar for teenagers with RDs, and they had a tight schedule. One thing we learned from analyzing our data was that many teenagers are tired and weary on weekends due to the side effects of their medication. Neither the surroundings nor the available time were ideal for creating a relaxed and open atmosphere in the focus group for teenagers held in the hospital. Nevertheless, the adolescents also provided invaluable data for this study, along with their experiences of long-term injection treatment.

9. Conclusion

This study contributes an in-depth exploration and description of needle-related pain and fear in children with RDs during their first medical subcutaneous injection and further into their daily lives with injection-based treatment. The findings provide novel insights into the complexity of the training sessions and the requirements placed on nurses to manage both technical and emotional challenges simultaneously. As expected, needle injections are associated with a fear of pain, but the fear often remains unspoken and is not properly addressed. The pain related to the needle insertion was less intense than the children expected, but they preferred to be better prepared for the stinging pain related to the injection. The study provides new insight into how the nurses' type of communication may affect children's emotional experiences and expressions during needle procedures. The findings indicated that the use of acknowledging communication tended to invite the child to become involved in the decision-making process during the training session. Understanding the findings from the perspective of Peplau's (1952) interpersonal theory emphasized the importance of the child–nurse–parent relationship, both in the hospital and at home.

Furthermore, this study highlighted the many challenges children and parents experienced due to the injection treatment at home, ranging from technical to emotional concerns. To complete the injections at home, the families used numerous coping strategies, although with the risk of the child being exposed to physical restraint. Creating routines and collaboration seemed to provide an essential resource for these families. During the course of this study, it became clear that children with RDs and their families need better follow-up and guidance to manage long-term injection-based treatment at home. The study confirmed the recurring problem of the lack of evidence-based management of children's needle pain and fear in clinical practice. The nurses perceived their educational role as significant; however, patient education for these children and parents takes place without sufficient guidelines and organizational structure and leaves the facilitation to each nurse's individual competence.

9.1 Implications for Clinical Practice

Short hospital stays make it challenging to combine the first medical injection with extensive patient education for children with RDs and their parents during hospitalization. Therefore, nurses should provide the first injection using evidence-based recommendations for managing children’s needle pain and fear to initiate the need for immediate drug delivery. Nurses need increased training in communication to improve the child–parent–nurse relationship, and to accommodate children’s need for assessment and acknowledgement of their fears and worries. Parents should have the opportunity to convey their concerns to the nurse and receive guidance on how to become the best coaches for their children. Nurses’ development of competence should include opportunities for reflection and guidance in clinical practice. Skills in pain management and communication can be learned by practicing with simulation. The findings of this study show that pediatric specialist nurses at outpatient clinics have better prerequisites and competence for follow-ups and comprehensive patient education. The division of providing the first injection and patient education gives the nurse an opportunity to take on one role at a time, while children and parents receive a step-wise approach that may increase their health literacy. These small changes in the facilitation for children with RDs who need injection-based treatment may provide a healthcare act from the child’s perspective, where the child’s experiences of pain and fear matter. To make information more accessible, internet and web-based solutions are important future resources.

9. 2 Implications for Research

In the original project plan, I aimed to develop and test an intervention to reduce children’s needle-related pain and fear. A promising avenue for future research might be to test an intervention that focuses on improving nurses’ communication skills and using evidence-based guidelines for procedural pain management. Furthermore, Peplau’s (1952) theory of interpersonal relationships discussed in this thesis may serve as a foundation for research focusing on the child–parent–nurse relationship. Health literacy is a concept in development that is of interest for research on children with RDs and their parents. Measuring health literacy could provide more targeted patient education for children and adolescents and meet the requirements for future self-management. Particularly relevant for future research is the use of the internet and web-based solutions as channels for information and follow-up for children with RDs.

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Children’s fear of needle injections: a qualitative study of training sessions for children with rheumatic diseases before home administration

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Abstract

Background: Treatment of rheumatic diseases in children often includes long-term needle injections, which represent a risk for refusing medication based on potential needle-fear. How nurses manage children’s fear and pain during the initial educational training session of subcutaneous injections, may affect the management of the subsequent injections in the home settings. The aim of this study was to explore how children expressed fear and pain during these training sessions, and how adults’ communication affected children’s expressed emotions.

Methods: This qualitative explorative study used video observations and short interviews during training sessions in a rheumatic hospital ward. Participants were children between five and fifteen years ($n = 8$), their parents ($n = 11$) and nurses ($n = 7$) in nine training sessions in total. The analysis followed descriptions of thematic analysis and interaction analysis.

Results: The children expressed fears indirectly as cues and nonverbal signs more often than direct statements. Three children stated explicit being afraid or wanting to stop. The children worried about needle-pain, but experienced the stinging pain after the injection more bothersome. The technical instructions were detailed and comprehensive and each nurse shaped the structure of the sessions. Both nurses and parents frequently offered coping strategies unclearly without sufficient time for children to understand. We identified three main adult communication approaches (*acknowledging*, *ambiguous* and *disregarding*) that influenced children’s expressed emotions during the training session.

Conclusions: Children’s expression of fear was likely to be indirectly, and pain was mostly related to the injection rather than the needle stick. When adults used an acknowledging communication and offered sufficient coping strategies, children seemed to become involved in the procedure and acted with confidence. The initial educational training session may have a great impact on long-term repeated injections in a home setting by providing children with confidence at the onset.

Keywords: Fear of needle, Subcutaneous injection, Home administration, Rheumatic disease, Juvenile idiopathic arthritis, Qualitative research, Video observation

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Background

Needle related fear is common, particularly in children [1]. It may impede vaccination and treatment programs based on medical injections [2, 3]. Children with rheumatic diseases like juvenile idiopathic arthritis (JIA) are especially vulnerable, as they are often treated with long-term subcutaneous injections of Disease-modifying anti-rheumatic drugs (DMARDs) and biologics [2, 4]. In one study, adults who had suffered from JIA for 30 years had lower physical function, lower health related quality of life and more pain than the general population [5]. Targeted medical treatment with DMARDs and biologics may improve the quality of life of JIA patients and may even bring the disease into remission [6]. However, the risk of relapse is significant and requires ongoing medication for years [7].

At home, subcutaneous injections are mainly administrated by parents or by children themselves. However, high levels of fear are associated with perceived pain during needle procedures [8], and the need for ongoing injections is a substantial stress factor for children and their families [4]. Therefore, alleviating fear is important [3]. Non-pharmacological strategies may improve children's coping [9–14], while some types of adult communication, such as reassurance, are associated with increased distress [15–17]. Distress describes several negative experiences like fear, pain and anxiety [18]. Historically, children have been ignored as active participants in *doctor-parent-child* communication [19] and are still rarely included in shared decision making [20]. In general, there is a lack of attention on children's emotions during medical consultations [21].

Clinical guidelines for the management of needle related fear and pain in children are mostly based on research into vaccination and venepuncture [22, 23]. Children with rheumatic diseases, who require repeated injections over time probably experience needle sticks differently from healthy children, who receive a limited number of vaccines. Thus, research on children in different contexts has been recommended to find methods to manage children's pain and suffering [24]. The way nurses relate to children and parents during training sessions and how they manage fears and worries may affect how injections are subsequently managed in home settings. Studying these training sessions may provide valuable knowledge for future clinical and educational recommendations. Children's participation in research is valuable, but it is essential to assess their vulnerability during the first medical injection carefully [25, 26].

The aim of this study was to explore children's expressions of fear and pain during training sessions for the home administration of subcutaneous injections. We also aimed to explore how nurses' and parents' communication affected children's expressed emotions.

Methods

Design

We chose a qualitative explorative design with an ethnographic approach, because it allowed us to describe and understand a phenomenon in a specific context [27]. We used video observation and subsequent short interviews with participants to obtain detailed data of ongoing communication and interactions between children, parent(s) and a nurse within a natural setting [28, 29].

Setting and participants

The study took place at a Norwegian university hospital that offered treatment to children with rheumatic diseases. When children were diagnosed and home medication prescribed, nurses educated children and their parents on how to self-administer needle injections. Usually, the education and first injection took place during a session in the paediatric ward, while subsequent injections were performed at home.

Participants in this study were nurses, children and their parents. To be included, nurses had to engage in patient education as a regular task during their daily work. Children had to be between five and fifteen years and in need of education on subcutaneous injections of DMARDs and biologics. Children with prior experience of injections were included if they needed a new education session due to new medication. Participants within each session represented an interactive unit in the social process studied, hereafter termed *a case* [27].

Data collection

Data was collected between June 2017 and December 2018. We used purposive sampling, which allowed us to choose participants that acted in the context in which we were interested [27]. The first author (KS) informed all nurses in the ward about the study prior to its onset. Nurses were invited to reflect upon positive and challenging consequences of participation during formal and informal meetings within the study period. A coordinating nurse assisted the researcher and ensured that only nurses willing to participate were connected with children (and parents) who met inclusion criteria. Participating nurses gave brief information about the study to children and parents identified as potential participants. If they agreed, then KS was contacted to provide more detailed information before children and parents consented to participate.

The observation procedure was pilot tested by KS during a training session without video recording. Video recording is considered an ideal method of gathering data in a natural setting [28] and causes minimal disturbance of the child-adult interaction. Two video cameras were placed in the room to capture a close-up of the child's face and a wide screen shot to obtain a full view of the training scene [28]. The use of GoPro cameras made it possible to prepare camera arrangement quickly. Video recordings began at the onset of the procedure and were stopped when nurses signalled that they were finished. The observer (KS) was present during the whole session and took field notes to contextualise the interaction [27]. It was possible to turn the video cameras off if they caused an extra burden for the child. In one case, participants changed places, making it difficult to view the child's face; however, KS could still observe the child's facial expression. A short interview with participants was completed immediately after the procedure in which they reflected on the experience of being filmed, and children were asked about their anticipatory fear of needles.

Data Analysis

The analysis drew on descriptions of thematic analysis (TA) [30, 31] and interaction analysis [32]. After following the six phases of TA, a systematic presentation of the findings with specific descriptions of the children's expressions of fear was created. To conduct an in-depth exploration of the interaction between nurse, child and parent(s), we carefully searched for *events* during which children showed distressed behaviour and looked for patterns that influenced changes in their expressed fear and pain.

All verbal conversations in the video recordings were transcribed by the first author (KS). Nonverbal signs and behaviour were marked. Fields of particular interest were underpinned and main impressions documented. All videos were viewed and reviewed by all authors. Some parts of the videos were studied during group sessions. Then, KS and HW coded the data. We were particularly interested in how children expressed negative emotions like fear and pain and how nurses and parents responded. The process used to identify emotions expressed indirectly and nonverbally was inspired by prior research in this field that used the Verona Coding Definitions of Emotional Sequences (VR-CoDES), a system for identifying patients' expressions of emotional distress during medical consultations [33, 34].

Participants' verbal and nonverbal communication was identified using a total of 67 codes. These were grouped into preliminary themes. All authors contributed to an ongoing reflexive clarification of themes to ensure that they worked well in relation to the data and research questions. In this phase of the analysis, we aimed to move from a summative position to an interpretative orientation and to develop a final thematic map (Fig. 1). We used the software tool NVivo 11 to obtain a systematic organisation and to perform the analysis [35]. NVivo's functionalities of viewing *coding stripes*, *comparing nodes* and *exploring hierarchy charts* were useful when looking for patterns across the dataset.

Trustworthiness

Generalisation in qualitative research is based on identifying social processes rather than from the representative sampling of individuals [27]. Credibility was achieved by describing participants' conversations and behaviour, including quotations. Confirmability was ensured by involving co-authors in all steps of the analytic process and by presenting the analytic steps from raw data to the results. Transparency was sought through detailed descriptions of the research process, allowing the reader to assess the research practice. To validate the fact that the presence of the researcher did not interfere with the procedure, each nurse was asked if the session had taken place as normal [36]. By providing sufficient contextual information about the study, we aimed to ensure transferability [37]. Triangulation between data from different sources, like field notes from the session and the short interview, contributed to its validation [27]. Consolidated criteria for reporting qualitative research (COREQ) were used as a guide to report this study [38].

Results

A total of eight children, seven nurses and eleven parents participated in nine cases. Characteristics of the cases have been described in Table 1.

All nurses were female with a mean age of 28.9 (26–34) years. Of the total sample, six had worked as registered nurses at this ward for less than one year and two nurses implemented a training session for the very first time. Four nurses had prior education into music, psychology, pedagogy or law. Those who refused to participate included one child and two of 20 available nurses. Findings suggested four main themes of interest, which have been summarised in a thematic map (Fig. 1).

A total of 20 defined subthemes were used to condense verbal and nonverbal communication and to describe coded actions and interactions. The structure of the session and the technical instructions given by nurses defined the context of these actions and interactions.

Structure and technical instructions

All sessions were carried out in patients' bedrooms, to which nurses brought the necessary equipment. Occasionally, the only table in the room was overloaded with the child's and parents' personal belongings, so medical equipment was placed in between these. Specific equipment used to distract children or help them cope during painful procedures was not available in the room. However, some children had their own toys or mobile phones available.

Nurses were responsible for safety during this complex procedure, that included medical, technical and hygienic aspects and to perform the session in a shortage of time. The technical information they provided was comprehensive and detailed (Table 2). Written or drawn age

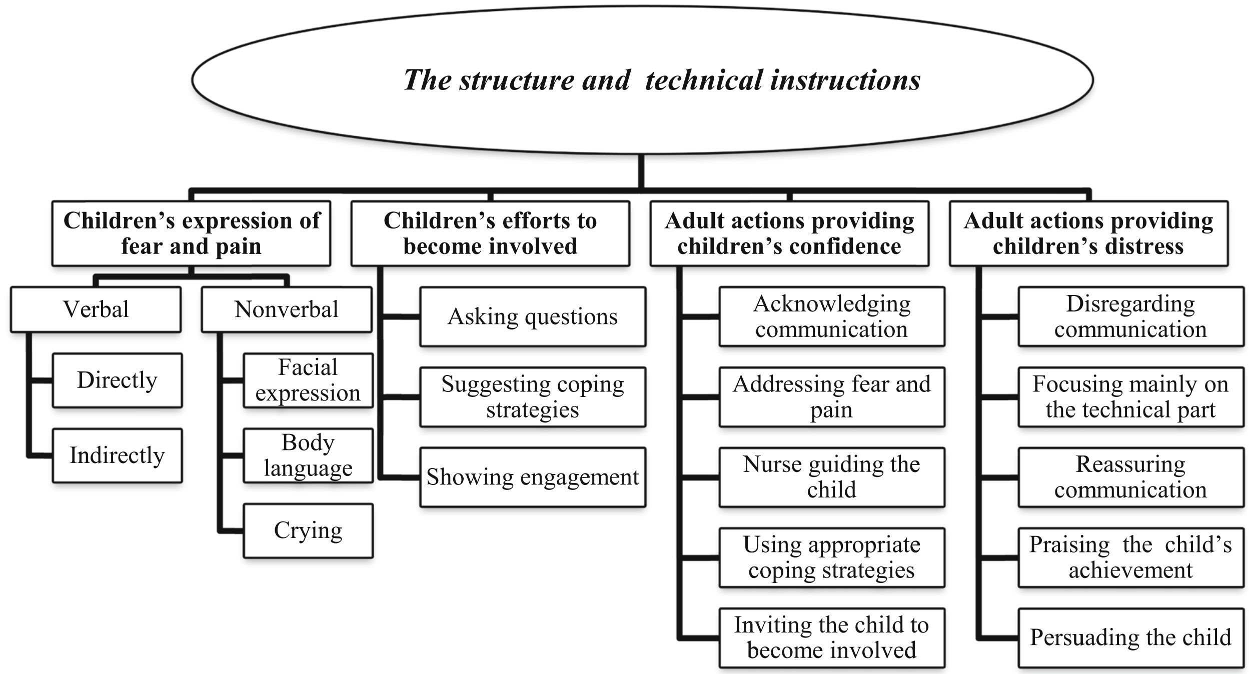

Fig. 1 Thematic map. The thematic map shows the four main themes and 20 defined subthemes used to condense verbal and nonverbal communication and to describe coded actions and interactions between participants in the training sessions. The structure and technical instructions defined the context

appropriate information was unavailable, so nurses sometimes offered to write down instructions or recommended that children and their parents watch videos on YouTube. In this study, two children had watched an educational video in advance of the session and were disappointed when they realised that the syringe differed from the pen for which they had prepared. Most children were invited to rehearse the self-administering of injections with the equipment and to poke needles into rubber skins, but the practice kit was sometimes different from the one they would use at home. Preparing for prefilled pens was easier and safer, but containing too large doses for children, only three children were offered this device. Thus, parents (and children) had to learn how to transfer a small dose from one syringe to another.

In four of the nine cases, the injection was given by the nurse, leaving the children and parents without the experience of administering an injection. No additional routine appointments for training sessions were scheduled.

Shortly after the training session we asked the nurses about their experiences of being filmed. The nurses stated being a bit nervous attending a video observation, but claimed they quickly got used to the camera and acted as normal as for other daily procedures at the ward.

Children's expression of emotions

In this study, seven of the eight children showed obvious signs of fear or worry about the needle injection. Their expression of fears varied from slight excitement to severe anxiety. Fear was mostly expressed indirectly or nonverbally. Only three children stated explicitly that they were afraid or refused to continue the procedure. Verbal expressions of fear have been exemplified in Table 3.

Children showed nonverbal signs, including a slight smile, insecure laughter, scratching themselves, intense wriggling, sitting stiffly in the chair, keeping their hands in front of their face, leaning on their parents, holding their hands on their stomach or shivering, moaning or crying with different strengths. Adolescents typically communicated fear nonverbally and consented to the injection despite being afraid, as exemplified in the following conversation:

> *Nurse: "As long as you find a technique that is okay for you … ."*
>
> *Child gasps, wriggles in the chair*
>
> *Nurse: "Shall we fill a real syringe then?"*
>
> *The child nods (Case 3)*

Table 1 Characteristics of the cases

Videos	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7	Case 8	Case 9
Child	Girl[a]	Girl[b]	Boy	Girl[c]	Girl	Boy[d]	Boy	Girl	Girl
Age (years)	10	5	14	15	8	15	15	12	12
Parents	two	one	one	two	two	one	one	one	one
Nurse	A	B[e]	C	B	D	E[e]	F	E	G
Performing injection	Nurse	Parent	Boy	Girl	Nurse		Nurse	Parent	Nurse
Session length	31 min	13 min	27 min	6 min	10 min	13 min	7 min	24 min	20 min
Medication (syringe/pen)	Enbrel (syringe)	Enbrel (syringe)	Enbrel (syringe)	RoActemra (pen)	Metex (pen)		Humira (pen)	Benepali (syringe)	Benepali (syringe)

[a] Diabetes type I, treated with Insulin pump

[b] Metex s.c a few times

[c] Injections by parents year ago, intravenous infusions before new education of s.c. injections

[d] The same boy in case 6 and 7

[e] Nurse B and E participated in two cases

Table 2 Detailed and comprehensive technical information

Codes	Illustrating quotations
Equipment and technique	*"You will hear a "click" when you push the bottom and then the chamber will be yellow"*
	"Your child is going to have 0,35 ml and this contain 1 ml"
	"You must put it in an angle of 45 or 90 degrees"
	"You must squeeze up the skin and inject"
	(All cases)
Warning	*"Watch out for sharp needles"*
	(Case 1,3)
Hygiene	*"You must wash the skin with this swab, to make sure it's clean"*
	(All cases)
Drug information:	
• Storage	*"You must take the medicine out of the refrigerator, 15 min before you inject it"*
• Waste	*"You will get a yellow box from the pharmacy"*
	(Case 3, 4, 6, 8)
Use of aids	*Syringes, pens, rubber skin (Case 1, 3, 5, 6, 8, 9)*

This child's anxiety was verbalised in the short interview after the procedure as follows:

> *Researcher: "How much did you worry on a scale from 0 to 10, where 0 is no worry and 10 is the most worrying thing you might think of?"*
>
> *Child: "Seven, I didn't know what to expect" (speaking with clear voice)*
>
> *Nurse: "But you looked very calm, even being so worried?" (Nurse looking surprised)*
>
> *Child: "Yes, it's inside of me" (Case 3)*

Children's fear did not depend on whether the injection was given by syringe or pen, as the device was new for each child. The three children with prior experience with injections showed different levels of fear; one stated being a bit worried (3–4 on a scale from 0; no worries at all to 10; worst worry imagined), one stated several times being afraid and denied to have the injection (screamed load), and one claimed not being worried at all, looking forward to skip the current intravenous infusions at the hospital every fourth week. In total, three children cried before the injection. Of these, two explicitly and repeatedly said that they were afraid and did not want to take part in the procedure. These children sat unmoving during the injection, but their facial expressions looked sad, and they searched for physical support from their parents. Nevertheless, the only child denying fears showed a great relief after the injection and shouted a loud *"yeah" (Case 4)*. Most children reported that the feared needle puncture was less painful than the subsequent stinging pain. Nevertheless, they would have liked to be prepared for this pain. It was one child that screamed out and cried for several minutes.

All children tried to become involved during the sessions, usually by being occupied with a task. They behaved in a more relaxed manner when playing with the equipment and their engagement sometimes increased when they received less attention from adults. For example, one child was lying in bed showing little interest but practiced more intensely when the nurse gave her attention to the parent (*Case 6*). Another child had two breaks during the session, because the nurse needed additional equipment, and the child utilised the breaks to share worries with the parent. When the nurse returned, the child asked directly if the needle would hurt.

The nurse replied:

> *"Some think it's painful and some don't. What people often feel unpleasant, if it hurts, it's not the needle stick itself but a slight stinging pain afterwards" (Case 9)*

Even though this child was afraid, she looked confident after the injection, stating that it was less painful than feared.

Children often asked practical questions about the injection site and whether to be aware of bubbles, or they tried to figure out what it would feel like. Three children were prepared with topical anaesthetic and examined their thigh to find a place where it would not hurt. The tone and volume of their voices rose as the hope of a

Table 3 Children's verbal expression of fear

Codes	Illustrating quotes and behaviour
Directly expressing fear	*"I am still afraid"*
Denying	*"I don't want to"*
Asking for time	*"I need to practice", "wait"*
Being quiet, spend time	*(Saying nothing or speak with low voice for a long time)*
Trying to understand	*"And it's not possible to take it slowly either"*
Challenging the adult	*"You didn't make to get it ready in time" (counting fast to 20)*
Bodily symptoms	*"I may be sick when taking blood samples – that happened once"*
Using onomatopoeia	*"Oh", "Ahaa", "Wow"*
Repeating neutral words	*"I must burst, burst, burst, burst …" (said with a raising tone in the voice)*

pain-free injection increased and lowered when they felt something touching their skin.

Adults' responses to children's fear and pain

Conversations during sessions usually included instructions from the nurse to the child and parent and practical questions from parents. Frequently, nurses did not ask children and parents about what they needed to learn or mapping questions related to prior experiences of fear and pain. Communication about fear and pain was sometimes initiated by nurses but was more often a response to children's nonverbal or verbal expressed emotions. Nurses suggested choices on positioning, holding hands and watching, but they generally missed to explain why these suggestions might help children cope during the procedure. All nurses praised the child (and parents) for their skills and willingness to perform the injection. The technical part of the procedure required much attention, and children's attempts to become involved and understand what was going on were not always perceived. We identified three main adult communication approaches (*acknowledging*, *ambiguous* and *disregarding*) that influenced children's coping (Table 4).

Acknowledging communication

In some cases, nurses acknowledged children's emotions and offered enough time to reflect on them (Table 4). These nurses managed to translate indirectly stated worries to an explicit fear and suggested possible coping strategies. Children acted more relaxed with increased engagement. In these cases, nurses and children reached a mutual understanding on the enactment of the procedure, and children expressed confidence and less pain than expected. In the cases in which nurses used acknowledging communication, parents were supportive of the communication between nurse and child. In one case, the parent mediated the communication, particularly when it came to a break (Case 9).

Ambiguous communication

In some cases, adults were aware of their children's fear but did not address it sufficiently. Coping strategies were suggested, but this was done too late or after the child had become distressed. Nurses in these cases made efforts to guide children through the procedure, but they failed to reach a mutual understanding (Table 4). During these procedures, both nurses and parents mainly used reassuring communication, that is, "*You won't feel much pain*", "*The needle is thin*" or "*This will do you good*". One child intended to inject the medication herself but stated explicitly that she was afraid and denied to watch. The nurse continued to reassure her, even when her distress increased. In addition, parents' activity increased, as they offered a mix of comfort, reassurance, physical support and slight attempts at distraction. Afterwards, nurses praised these children for being brave and invited them to talk about their experience of pain. Children exposed to ambiguous communication cried, looked away and physically held on to their parents during the procedure. After the injection, they expressed relief and looked both proud and embarrassed.

Disregarding communication

In some cases, both nurses and parents responded to children's actions rather than their concerns. For example, the following exchange occurred when one child touched the skin after topical anaesthetic was applied:

> *Parent: "You shouldn't have touched it (because it was clean)"*
>
> *Child: "I just wanted to feel … ."*
>
> *Nurse: "It's okay, we can clean it again" (Case 2)*

This child had shown several signs of fear and tried to become involved during the procedure. The nurse repeatedly turned to the parent and did not respond to the child. When the child shouted out loudly, "*No I don't want to do it*", the parent offered to look at the preparation, but the child showed no interest. This child cried for a long time after the injection and reported severe pain. In another case (Table 4), both the nurse and the parents used reassurance to make the child accept the injection. They suggested coping strategies and tempted the child with a reward. This child directly stated severe fear but was not offered sufficient time for reflection and remained afraid.

In these cases, the children gave up their protests, received the injection and expressed more pain than others. They looked sad, and their parents had to comfort them for long time afterwards even though nurses praised the children for their achievement and gave them rewards.

Discussion

The main finding of this study was that for the most part, children expressed fear indirectly or nonverbally. Anticipatory fear appeared more bothersome than the pain experience itself. We also found that adults' approach to communication affected children's opportunity to express their emotions. Children became more involved when nurses acknowledged their fear. Both nurses and parents frequently offered coping strategies unclearly without sufficient time for children to understand.

Table 4 Examples of three different main approaches by the adults towards the child’s fear

1. Acknowledging communication		
Nurse activities	*Communication and interaction*	Child response
Addressing fear	*Nurse: “So, what you might do when I give you the shot; is to choose to look at it, or you can look at mummy or daddy, but it might hurt, right?”*	Becoming engaged
Suggesting coping-strategy; time to reflect	*Child: “Yes” (nods)*	
	Nurse: “When you feel the needle stick, you might squeeze your mother’s hand as hard as you feel it”	
Guiding the child (and parents)	*Child: “And I can think that when its finished; it’s finished, and it’s a week until next time..”*	
	Nurse: “Yes”	Showing confidence
	Child: “… and then, it might not hurt so much …” (*Case1*)	
2. Ambiguous communication		
Nurse activities	*Communication and interaction*	Child response
Addressing fear	*Child: “Shows an insecure smile (non-verbal fear)*	
	Nurse: “I do understand if you worry about the needle-injection, it might hurt”	Not time to become engaged
Suggesting coping-strategy; unclear, no time to reflect	*Nurse: “Do you want to look at it or to mummy or ….?”*	
	Child: “I don’t know”	
	Nurse: “You do as you like, what you think is best – okay? (no answer) here it is; just like a pen don’t you think? The medication is in here; not so much - and you can see that this is the one getting yellow – right? (hearing the nurse take a deep breath) -, then it’s nice and quiet”	
Taking control	*Child: Whispers something impossible to hear*	
	Nurse: “Shall we just have it done? Yes, I will give it here”	Crying
	Child: “Oh – (cries quietly)”	Surrendering
Praising the child	*Nurse: “Do you want me to count before I do it?*	
	Child: (no answer)	
	Nurse: (Gives the shot). *There we are (with laud voice) – very brave!”*	
Talking about the experience	*Child: “Yes”*	Showing relief and embarrassment (confused)
	Nurse: “How does it feel? Was it painful?”	
	Child: “It didn’t hurt so much” (*Case 7*)	
3. Disregarding communication		
Nurse activities	*Communication and interaction*	Child response
Reassuring	*Child: “The needle stick will hurt”*	Continuing to express fear
	Parent 1: “It will be over soon”	
	Child: Speaks in a very low voice	
Suggesting coping strategy; unclear, and persuading	*Nurse: “You will hardly notice anything”*	
	Child: “Yes, but I don’t dare”	
	Parent 2: “Come on, you can hold on to me”	Crying
	Child: “I don’t dare” –(cries)	Protesting
	Parent 2: “Breath”	
	Child: “I don’t want to” – (cries)	
Offering a prize	*Nurse: “I will find you a prize afterwards”*	
	Child: “I don’t want to” – (cries softer) (Case5)	Surrendering

Children's subtle communication of fear and pain

We expected that children would worry about the needles, as the fear of needles is common among children [1, 3]. Prevalence was expected to decrease during adolescence to a range between 20 and 50% [3]. In our study, adolescents' fears and worries were evident, and these were mainly expressed nonverbally or indirectly. This was in line with previous studies on children in cardiologic and oncologic medical consultations in whom worries were commonly communicated as subtle verbal and nonverbal cues rather than explicit concerns [33, 39]. A *cue* is a verbal or nonverbal hint suggesting an underlying unpleasant emotion lacking clarity, whilst a *concern* may be defined as an explicit expression of a current or recent unpleasant emotion [34]. In the videos, we identified slight smiles, insecure body language, lowered voices or slow movements as typical *cues* of fear. Worries are more likely to be expressed as *cues* than as *concerns*, making them difficult to detect [40]. Therefore, nurses did not always perceive fear until the short interview after the procedure.

The most anxious children reported more intense pain than those who were less anxious, which corresponded with research showing that high levels of fear are associated with increased pain during needle procedures [8]. Pain perception depends on many factors, like how adults behave in the situation and the child's emotional state and coping skills [24]. Before the procedure, nurses rarely communicated with children about their worries, even though these children were able to describe their emotional state eloquently. Children experienced the stinging pain after the injection as more painful than the needle stick, which emphasised their need for concrete information about this expected pain and a need to have their pain assessed. Systematic assessment of children's pain and fear, adjusted to their level of maturity, is widely recommended in the literature, and several tools are available for this purpose [12, 41–43]. From a biopsychosocial perspective, acquiring information about patients' emotional state by identifying cues and concerns is equally as important as gathering information about their physical condition [34]. Our findings suggested that asking children about their worries before a potentially painful procedure gives them an opportunity to verbalise their concerns.

The most anxious children seemed to distance themselves mentally when the injection came closer. They gave up their verbal protests and received the injection, sometimes after repeated persuasion from nurses and parents. These children looked sad, and their body language was stiff or retiring. They avoided looking at the nurse, and they held onto their parents physically. Similar behaviour has been described as surrendering and is one way for the child to regain control during a needle procedure [14]. A study of preschool children who had venepuncture used the term endurance to describe this resistive expression, which occurs after children have given up protesting and escaping [44]. No children in our study tried to escape physically, as they were old enough to understand the reason for the injection. Surrendering behaviour may have been a way for them to prepare for an unpleasant situation, though it may have implied their compliance rather than their acceptance of the procedure [14].

Adults' approach to communication

Nurses often paid more attention to details of the needle procedure than to children's signs of fear. Administering subcutaneous injections to a child is a complex task and requires specific knowledge that may be demanding, especially for nurses who are performing a training session for the first time. Nurses ensured that they selected the correct injection site, the right angle of needle insertion and the right temperature of the medicine per recommendations in the literature [45]. However, their approach to communication may be important for how children express their emotions. Nurses who were able to recognise and understand the role of emotional content in a conversation seemed to form good relationships with both adults and children, which are needed for the development of shared management in medical care [21]. The nurses' experience was expected to influence their communication, but we observed that some of the less experienced nurses managed the communication very well. This observation may have been related to prior experiences and education that some of these nurses had, rather than their education and experience as nurses.

When nurses had an acknowledging attitude towards children, this provided them with *space* in which to express both positive and negative emotions. Providing space has been explained by healthcare professionals as giving patients the freedom to disclose personal thoughts and feelings while paying attention to their needs and worries [40]. Taking a break provided the child with additional space that seemed to influence them positively. When nurses moved too quickly, even if they recognised children's fear, the message became ambiguous, even if the content was relevant. When children clearly stated that they were afraid, adults (both nurses and parents) sometimes escalated their number of suggestions. Suggestions became more geared towards persuading children to finish the injection rather than being aimed at reducing children's distress. Children did not seem to understand or trust these suggestions. Children may have been less distressed if information and a choice of coping strategies had been provided prior to the injection procedure [23, 24].

Acknowledging communication has been characterised by an understanding of children's perspectives that confirms their experience and by appreciating children's emotions as well as their actions or achievements [46]. We found that when children were acknowledged, they reached a mutual understanding with the nurse and became more involved in the procedure. These children showed more confidence throughout the procedure. In order to give children essential acknowledgement, nurses must be self-aware during their interactions with children and be sensitive to nonverbal and verbal communication [46]. This is a demanding task, and special competence is required by the nurses. Both children and parents acted more confidently when nurses guided them, showed predictability and took control over what was happening. Other studies have emphasised children's need for age appropriate information and guidance and have shown that children's choices should be an integral part of decision making [13, 47].

Both nurses and parents frequently used reassurance (that is, *"It will be okay"* or *"It won't hurt")* as a natural way of comforting children. This usually did not decrease children's fear. Adult reassurance has been shown to increase children's distress during medical procedures [16, 17, 23] and is an example of communication that reduces space for further disclosure compared with a more acknowledging approach [39]. We observed one exception in which parents provided reassurance while the nurse reached a mutual understanding with the child. This child stayed focused and confident. Previous research has emphasised the complexity of reassurance and suggests that adults' facial expressions, vocal tones and verbal content play an important role in how reassurance is perceived [15].

In the cases characterised by ambiguous or disregarding communication, we observed that children's confidence increased when afterwards, the nurse or parent(s) reflected on the experience and acknowledged the children's braveness. Helping children to express their emotions after a painful procedure and shape a more positive memory has a positive influence on later pain experiences [48].

Children's willingness to be involved

Children often showed positive engagement when playing with equipment, and some children suggested their preferred coping strategy. However, nurses did not always follow up on these opportunities to form a relationship with the child. Children lack equal opportunities to share their views and participate in decisions regarding their care [49]. Incomplete use of acknowledging communication and coping strategies may explain children's chances for participation. The children with prior experiences of needle injections appreciated just as much the preparation and training as the other children. Being aware of building this important relationship with every child may prevent the risk of proceeding too fast or skip important steps in the training session.

Appropriate distraction is widely recommended as a way to manage procedural distress [9–11, 47]. In this study, only two children realised that distraction was helpful. Distraction must be experienced as safe and voluntary to be supportive, and children should recognise adults' actions and believe that they can manage the procedure [13]. The aim of training sessions was to teach children and parents the injection technique. Most children were encouraged to watch the procedure, and they tried to involve themselves even though they were afraid. However, when children are highly anxious, it might be more appropriate to offer distraction and then use a stepwise training schedule for home administration [45]. It seems of utmost importance to assess children's fear before choosing an appropriate coping strategy. The Distraction in Action Tool (DAT) is a promising screening tool that parents and clinicians have found useful in assessing children's risk for distress and in teaching distraction techniques that can be used during needle stick procedures in an Emergency Department [50].

Two children were willing to engage in decisional control and managed to self-inject the very first time. They were encouraged and closely guided by nurses, who provided enough time and space. Their parents stayed calm and supportive. Such decisional control and choice between a few options may be appropriate, whilst unclear or open ended suggestions, for example, *"How do you like it?"* may expect too much of children, delay the procedure and leave the child in distress [17].

Parents need knowledge to support their children during painful procedures

Parents knew that they were supposed to leave the hospital after the training session and administer the next injection at home without any further training. This may have caused them to hesitate or push too hard to finish, so their suggestions and intended emotional guidance were not always perceived by children. Thus, children remained in a state of fear, which is known to undermine the effect of pain-relieving interventions [8]. This challenging situation worried nurses, and as they were unable to offer a follow-up appointment, they advised parents to watch a YouTube video or write down the main messages. Parents are often in a state of shock, fear and disbelief shortly after their child has been diagnosed with a serious disease [51]. Therefore, it may be difficult for them to guide and comfort their child through the procedure. Parents need knowledge and tools provided by competent healthcare providers to support their child and manage their own distress [17, 22].

Strengths and limitations

To our knowledge, this is the first in-depth study examining training sessions intended to teach the home administration of subcutaneous injections of DMARDs and biologics. Although the sample was small and represented only one single hospital, the present sample contained enough variation in key demographics to identify important patterns related to children's expression of fear and how adult communication affects children's emotions. We used video observations to explore real-time actions, producing a valuable foundation for further research and the development of clinical practice.

A limitation is that the video observations only examined scheduled training sessions. We assumed that children repeatedly received informal information about injections during their hospital stay, which could have increased their educational level. In addition, children who met inclusion criteria during the study period might have missed out on an invitation to join the study. Finally, being recruited and filmed engaging in a medical procedure during a busy day at the hospital required extra effort from each nurse.

Conclusion

Children with rheumatic diseases worry about needle pain and experience the stinging pain that occurs after an injection bothersome. Fear is usually expressed indirectly as cues and nonverbal signs rather than direct statements. When adults acknowledge children's emotions and offer sufficient coping strategies, children become engaged in the procedure and act confidently. How nurses and parents communicate and interact with children and each other seems essential for children's coping during the procedure. The initial educational training session may have a great impact on long-term repeated injections in a home setting by providing children with confidence at the onset.

Implications for clinical practice and further research

Based on these findings, we have suggested that this procedure should be initiated by asking all children (who are able to talk) about their fears and acknowledging their emotions. This simple change may improve children's experiences of fear and pain during procedures. Small adjustments like these have been significant in shaping children's future experiences of needle injections [8]. Education on needle injections for home administration requires organisational preconditions like guidelines, informational materials and suitable equipment for training and distraction. To practice technical skills and take care of emotional concerns in one session is a huge challenge, and nurses who have this as part of their job need knowledge and guidance. Most children would probably benefit from having more than one training session with age appropriate preparation, and it may be helpful to assess their fear and use a coping strategy. This may increase their confidence with subcutaneous injections. Further research, such as a larger longitudinal study and the development of a stepwise systematic educational program is warranted.

Abbreviations

DMARDs: Disease-modifying antirheumatic drugs; JIA: Juvenile Idiopathic Arthritis; TA: Thematic analysis; VR-CoDES: Verona Coding Definitions of Emotional Sequences

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Authors' contributions

KS has contributed at all stages, from the design of the study to the final written version of the paper. HS and HW contributed substantially to the conception and design of the study. GK, HS and HW have been involved in the analysis and interpretation of the data. All authors revised the manuscript and approved the final version.

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Availability of data and materials

The datasets (video recordings and written transcripts) have been stored at Services for sensitive data at UiO and have not been made publicly available. This is due to the high risk of the public identifying the participants, as they have been filmed.

Ethics approval and consent to participate

The study was approved by the South Eastern Regional Committee for Medical and Health Research Ethics in Norway (2016/1749) and was conducted according to the code of ethics of the Helsinki Declaration [52]. Oral and written consent was obtained from all nurses, parents and children ≥12 years. Children < 12 years gave oral consent.

Consent for publication

Not applicable.

Competing interests

The authors have no competing interests.

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Pediatric Rheumatology

RESEARCH ARTICLE

Open Access

I don’t want to think about it: a qualitative study of children (6–18 years) with rheumatic diseases and parents’ experiences with regular needle injections at home

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Abstract

Background: Overall outcomes of pediatric rheumatic diseases (RD) have improved due to treatment with biologic agents and methotrexate. For many children, this treatment often entails regular needle injections. Pain and fear of needle injections are common in childhood, but how children and parents handle long-term needle injections at home has not been fully explored. This study aimed to explore how regular needle injections affect children with RD and their parents in their daily living.

Methods: This explorative qualitative study used individual interviews and focus groups to ensure a comprehensive investigation of the topic. Children aged 6 to 16 years ($n = 7$) and their parents ($n = 8$) were interviewed individually 4 to 6 months after the onset of needle injection treatment. The focus groups included children aged 11 to 17 years ($n = 9$) and parents ($n = 8$) with a minimum of 6 months of experience with injection treatment. Data were analyzed using thematic analysis.

Results: The main themes; “challenges,” “motivational factors,” and “routines” captured experiences and strategies that influenced the continuation of needle injections at home. Many children feared the moment immediately before the needle stick, although they had become accustomed to the pain. Most parents felt insecure about handling needle injections and lacked follow-up from healthcare providers. The children’s experience of treatment effects and self-confidence were essential to maintain motivation for further injections. A number of coping strategies helped children focus away from injection related discomfort, often discovered by chance. Facilitating firm routines and shared responsibility within families helped children develop self-confidence during the procedure. Children and parents struggled to find suitable information on the Internet.

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Conclusions: Children and parents experienced long-term needle injections challenging. They used their own limited resources and cooperated within the families to create routines and to introduce coping strategies necessary to manage and keep up with the procedure. Although the injection itself was not experienced very painful, the discomfort, worries and impact on daily life represented far more than a little needle stick, and thus needs more attention from healthcare providers.

Keywords: Needle injection, Child, Adolescent, Needle fear, Rheumatic disease, Home administration, Coping strategies, Routines, Family cooperation, Qualitative research

Background

Overall outcomes of rheumatic diseases (RD) in childhood have improved substantially due to new treatment programs, including the use of biologic agents and methotrexate combined with physical activity [1–4]. Children and parents must administer most of these drugs via regular needle injections. Pain and fear of needle injections are common among children [5, 6] and may cause reluctance to use injections and non-adherence to treatment [7, 8].

Management of needle-related fear and pain has remained suboptimal even though pain management strategies are available [9, 10]. Non-pharmacological coping strategies have proven effective in reducing distress due to procedural pain and have been shown to assist children's coping [11–15]. Even so, children are still undergoing physical restraint by parents and health care providers (HPs) when they refuse painful procedures [16, 17]. Children's recollection of distress during procedures may cause anticipatory fear and increased pain during future procedures [9, 18]. In some cases, repeated painful procedures may lead to post-traumatic stress syndrome, non-adherence to medical treatment, and aversion to health care later in life [10, 19].

The health care of chronic illness has developed towards an increased emphasis on self-management, where a patient's condition and the subsequent treatment are taken care of at home [20]. Children with RD and their parents normally have a short hospital stay, during which examination, initiation of treatment, and injection training take place [21]. Children and parents are expected to conduct regular needle injections at home. For children, self-management is a developmental task that starts early and changes as they grow older [22]. How children and their families handle long-term injection-based treatment may impact adherence to treatment and general self-management, and to date, this has not been fully explored. This study aimed to explore how regular needle injections affect children with RD and their parents in their daily living.

Research questions were as follows:

1. How do children and parents experience long-term needle injections administered at home?
2. What characterizes children's and parents' use of coping strategies at home?

Methods

This study was part of a larger research project investigating children's fear and pain related to long-term needle injections. The first study of the project used video observations to explore children's pain and fear during training sessions at a hospital ward in Norway [21]. The current study used an explorative design with individual interviews and focus groups to capture the complexity of drug administration at home. Data was collected through these two qualitative methods to enlarge the width and depth of the investigation [23].

Participants

We used a purposive sampling strategy to include information-rich cases [23]. Children aged 6 to 16 years and their parents were interviewed individually 4 to 6 months after they started using needle injections. Participants in this study had been part of the initial video observation study [21] and had consented to be invited to participate in this study. Participants from all families except one were included, and one child was represented by both the mother and father in separate interviews.

Children between 10 and 18 years with RD and a minimum of 6 months of experience with regular needle injections were included in the focus groups. The included participants varied in age, diagnosis, medication, and duration of injection experience, but sufficient group homogenousity was ensured to stimulate a climate promoting exchange of sensitive information [23]. Parents who participated in the focus groups had children under 18 years old with RD and had experience in handling needle injections at home for more than 6 months. Children and parents who participated in the focus groups were not necessarily related to each other. Recruitment efforts involved social media announcements by the Norwegian League Against Rheumatism (BURG) and the Norwegian National Advisory Unit of Rheumatic Diseases in Children and Adolescents (NAKBUR), which also provided study information to their members. Focus groups were limited to four or five children in each group and had an age span of 3 years, because the interests, experiences, and socialization of children may change substantially during childhood [24]. Parents were divided into two focus groups based on practical considerations and the fact that smaller groups work best to provide high interaction between the participants [23].

Procedure

In-depth, semi-structured individual interviews were conducted by the first author, KS, and took place between March 2018 and March 2019. KS has long experience as a nurse working with children at different ages both clinically and in research. She formed a relation with the families during the video observation, that took place 4 to 6 months, before the individual interviews, but was not employed at the department nor involved in the regular treatment of the children. Average interview duration was 48 min (range 18–71 min) for parents and 23 min (range 14–47 min) for children. To ensure that participants felt comfortable, they were all given the option of being interviewed at home, but two children and three parents preferred to be interviewed at the hospital. The two youngest children, at the ages of 6 and 9 years, chose to have one parent present and appreciated the availability of drawing equipment during the conversation. For the remaining interviews, children and parents were interviewed separately.

Focus groups took place between March and April 2018. The author, KS, was a moderator in all groups, and HW and HS acted as secretary in two groups each. Children and parents were informed that the researchers were not involved in the treatment of the children, and that this work was associated with a doctoral dissertation. The user participant, who was 18 years old at that time, attended the two focus groups for children. She had long experience living with RD and handling injections, and could initiate some of the discussions by sharing her own story. She also took notes, which was discussed with the moderator and the secretary just after the focus groups. The average duration of focus group discussions was 70 min (range 45–100 min), and they were conducted in appropriate locations. Food and drinks were offered, and participants were engaged in ice-breaking tasks before the focus group started.

Separate interview guides suitable for adults and children of different ages were carefully developed and followed descriptions by Green & Thorogood [23], and the content were discussed in the research team and with the user participant. The main topics and questions were emailed to each family before individual interviews to initiate their preparation. The interviews were facilitated as a natural conversation, talking about the prepared topics and main questions, and the subquestions were used only if the participants did not mention the topics. The main topics in the focus groups were similar to those in the individual interviews (see Table 1). All conversations were audiotaped, and main impressions were written down immediately after each interview, while the secretary took notes during focus group discussions. Data encompassed the transcribed audiotapes and these notes. Instead of seeking *data saturation*, a concept tied to grounded theory [23, 25], we sought to include transparancy throughout the study and thorough descriptions of the sample. Malterud (2016) has proposed the concept *information power,* indicating that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed [25].

Analysis

Data were analyzed using thematic analysis [26, 27], and the software tool NVivo 11 was used to structure and analyze the data. Audiotapes were transcribed by KS, and ideas for coding and analysis were noted throughout the transcription phase. Initial inductive coding of individual interviews resulted in 61 codes, which were structured into four preliminary themes and twelve subthemes. Interviews with children and parents were coded and analyzed separately. Codes from the analysis of the interviews were used deductively to analyze the data from focus groups, while keeping an open mind to the appearance of new information. KS completed the initial coding and shared excerpts with the other authors continually. All authors met several times during the process to discuss the analysis and to redefine themes and subthemes before reaching a consensus on the final results. The analytic steps from the generation of codes to the generation of main themes have been exemplified in Table 2.

Credibility was established through broad discussions throughout the study and by including quotations from different participants in the paper [23]. Triangulation between data from different sources, including individual interviews, focus groups, and written notes validated the analysis. Member checking during interviews ensured the correct perception of participant responses, and findings were assessed by the user participant. The report of this study was guided by the consolidated criteria for reporting qualitative research (COREQ) [28].

Results

A total of 16 children (11 girls and 5 boys) and 16 parents (12 mothers and 4 fathers) shared their experiences of long-term needle injection use at home. Of these, seven children and eight parents were interviewed individually, and nine children and eight parents participated

Table 1 Content from the individual- and focus group interview guides with children

	Individual interviews with children	Focus groups with children
Introduction	Establish contact and tell about the study Talk about everyday life, something the child is interested in Offer the child to draw, write or something to puzzle during the interview	Establish contact and tell about the study Introduce each other (playing a game) Agree on some house rules: • What being said in the room is kept there, only the researchers are allowed to listen to the recordings • Don't speak at the same time • We don't need to agree, everyone may have different experiences Offer to write or draw
Themes and questions	Can you tell about how it is to have needle injections? • About how it feels (if it hurts, what are you doing to decrease pain or worries?) • About how it takes place (who's doing what) Can you tell about the first time you got the injection at the hospital? • Do you remember if it was painful or if you worried? • Could anything have been done differently? Can you tell about your disease and if the injection helps you? What do children need to know when they start with needle injections? What do you think about continuing with needle injections? Is there anything else you want to tell?	Can you tell about your experiences with needle sticks? • About the frequency and length of the injection • About pain and worrying How it feels (pain and worries) If it hurts or you worry, what are your actions to decrease these? Describe what's going on in connection with the injection • What do you do before, during and afterwards • What do the adults do? Tell about the education for needle injections In what ways do the injections affect you in school, home and leisure activities? What do you think about continuing with needle injections? What do children need to know when they start with needle injections? Is there anything else you want to tell?
Finish	Summarize the main content in the conversation and ask if I have understood it correctly Thank you very much for sharing your experiences! (Give the child a little present)	Summarize the main content in the conversation and ask if we have understood it correctly Thank you for sharing and discussing your experiences! (Give them a little present)

in focus groups. There was variation in rheumatic diagnosis, medication, and duration of injection-based treatment (from 4 months to 15 years). Participant characteristics have been presented in Table 3, and the source of each quotation has been marked as II (which indicated an individual interview) or FG (which indicated a focus group). Main themes have been illustrated in Fig. 1.

Challenges

Children and parents reported challenges associated with regular home administration of needle injections. Their stories included physical pain and emotional distress related to the injections and other painful procedures, like blood samples, joint injections, and peripheral vein cannulation (PVC). Additional challenges were connected to the handling of equipment and the prevention of side effects of the drugs.

Most parents felt insecure when they became responsible for the medical treatment of their child after discharge from the hospital, which was illustrated by the following:

> "*I was thinking, 'Oh my god – this is a huge responsibility!' I didn't feel competent. I have a sister who is a nurse; she gave me some advice. I thought this was unjustifiable; it should have been a nurse doing this.*" (Parent of a 14-year-old boy, II)

Many parents reported that their handling of the injections at home was hardly ever explored at regular follow-up consultations. Several parents also mentioned a lack of psychological advice on how to assist their child's coping with pain and fear.

Children were mainly concerned about how they could avoid focusing on the needle sticks. Most children had become accustomed to the injections but reported that they still feared the moment before the needle stick even if it did not hurt much. This was even evident by children performing the injection themselves. Parents were frightened by the prospect of inserting a needle into one's child, although a father described this as being easier than expected, "*As sliding a warm knife through butter.*" Children and parents compared the experience with other needle procedures. Most children rated blood sampling as more painful than subcutaneous injections, depending on who performed the test.

> "*They are not so skilled with children at the local office. It was very painful, and I usually don't mind blood tests at all when performed by a known person.*" (11-year-old child, FG)

Many children stated that being given sufficient information and being able to decide some parts of procedures increased their trust in those performing painful procedures. Bad experiences affected children and parents for

Table 2 Example of the pathway from codes to main theme

Codes from the individual interview data	Codes added from the focus groups data	Sub-Themes	Main theme
Children: Knowledge Appraisal Getting used to Distraction Control Emla	**Children:** Not Emla Relaxation Quick performance Cooling	Coping strategies	Routines
Parents: Relaxation Appraisal Getting used to Distraction Control Humor Play Emla The child's understanding	**Parents:** The child's understanding Cooling Negotiation Physical Restraint		
Children & parents: Regular practices Handling the equipment Teamwork Adjustments Relations Responsibility Self-injection	**Children:** Self-determination Having a friend present **Parents:** Support from BURG	Facilitations Daily life Prevention of side effects Shared decision making	

Abbreviation: *BURG* Norwegian League Against Rheumatism

a long time, especially if the child had been physically restrained during the procedure.

> "*It almost felt like abuse, when one person held him down, another stretched out the hand and … . he still doesn't like PVC! But he has gone a long way up until today - just need a warm hug and to squeeze my hand …* " (Parent of 14-year-old child, FG)

Many parents reported that they admired their children for their willingness to receive needle injections, but they also talked about the difficulty of interfering with situations where HPs pressed hard to get a procedure done. One child had developed severe needle phobia after a bad experience and had refused the recommended subcutaneous treatment. Her mother felt miserable about being unable to assist her child. At the beginning of home treatment, some parents had used physical restraint, by holding their child to carry out the injections, but later realized how this traumatized both the child and themselves, and they could not continue.

Parents talked much about their efforts in handling equipment, preparing for the treatment, and implementing it. Their struggle to transfer a small drug volume from one syringe to another or to hold the correct grip sometimes resulted in spoiled drugs. Many said that they lacked written information and had to rely on their memory of oral instructions given by nurses at the hospital. Most children, however, stated that they could remember details from the training session, "*I learned that we should not stick the needle straight down, but slightly slanted*" (12-year-old child, II). Such statements indicated children's quick learning and high self-confidence concerning technical equipment. Some parents told how their child even guided them at home.

> "*She (our daughter) looks after us, that we don't inject too slow or too fast … and told me once, 'Mama, it's due to the side effects we must take the injection in the evening.' She remembers everything!*" (Parent of 12-year-old child, II)

Table 3 Characteristics of study participants

Participants	**Characteristics**
Individual interviews	
Children:	
Gender	5 females, 2 males
Age at interview	6–16 years (mean 12 years, 4 ≤ 12 years and 3 > 12 years)
Disease duration	4–6 months (mean 5.6 months)[a]
Diagnosis	Oligo JIA (2), Poly JIA (2), Enthesitis-related JIA (1), Juvenile dermatomyositis (1), Behcets disease (1)
Medications received	Methotrexate (oral or s.c.) in combination with etanercept (Enbrel/Benepali) s.c (3) or tocilizumab (RoActemra) s.c. (1), etanercept (Enbrel) s.c. (1), methotrexate (Metex) s.c. (1) and adalimumab (Humira) s.c (1)
Parents (of the same children):	
Gender	7 females, 1 male
Focus groups	
Children (in two groups):	
Gender	6 females, 3 males
Age at time of focus group	11–13 years (mean 12 years) in the first group and 14–17 years (mean 15.8 years) in the second group.
Disease duration	6 months – 15 years (mean 8.1 years)
Diagnosis	Unspecified JIA (5), Oligo JIA (1), Poly JIA (2), Systemic JIA (1) (self-reported)
Medications received	Methotrexate (oral or s.c.) in combination with etanercept (Enbrel/Benepali) s.c (3) or tocilizumab (RoActemra) s.c. (1), methotrexate (Metex) s.c. (3), tocilizumab (RoActemra) i.v. (1) (earlier s.c. medication) and methotrexate oral (1) (earlier s.c. medication)[b]
Parents (in two groups):	
Gender	5 females, 3 males
Disease duration (child)	1–15 years (mean 7.2 years)
Diagnosis (child)	Unspecified JIA (5), Poly JIA (2), Systemic JIA (1) (self-reported)
Medications received (child)	Methotrexate (oral in combination with etanercept (Enbrel) s.c (2) or adalimumab. (Humira) s.c (1), methotrexate (Metex) s.c. (2), and methotrexate oral (2)

Number of participants: (n), *Abbreviations*: *JIA* Juvenile Idiopathic Arthritis, *s.c.* subcutaneous

[a] One child was diagnosed 10 years ago and had previous experience with s.c. injections, but after several years without s.c. injections she was readmitted 6 month earlier and needed updated education

[b] Due to severe side effects of injections or severe needle–fear converted from subcutaneous to oral administrations

Concerns about drug-related side effects were especially highlighted by children in focus groups. They stated that oral and subcutaneous methotrexate could cause nausea, vomiting, and tiredness. Some said that they had started feeling sick when observing something yellow, smelling or tasting anything that reminded of the drugs, or even just thinking about them. Children who were interviewed individually did not talk explicitly about such side effects, but their parents reported that precautions were taken to prevent potential discomfort. Some parents uttered their worries and mixed feelings about the drugs.

> "*After all, these medicines are no good. I panic when I read about the scariest side effects. However, getting better prognosis for the disease is positive.*" (Parent of 9-year-old child, II)

Motivational factors

The children had all suffered from pain, joint stiffness, reduced physical activity, and other discomforts to different degrees before being diagnosed. Many parents described the relief they felt when they realized that their child suffered from a treatable disease, and this motivated injection treatment. Their conclusion was that "*this is something you just have to do.*" Children's experiences of improvement after starting treatment increased parents' and children's motivation to continue. Some children reported that a lack of

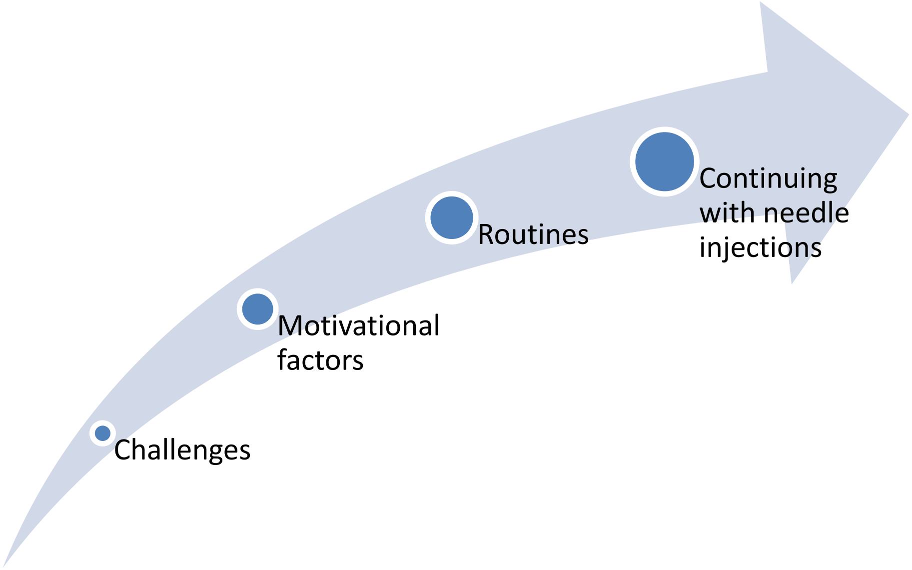

Fig. 1 Main themes. The arrow illustrates the continuum of the three main themes capturing children's and parents' experiences and strategies influencing the continuation of needle injections at home. Continuation of injections at home indicates adherence to treatment

effects or bothersome side effects decreased their motivation to continue.

> *"I have taken injections at home before, but when the drug made me very sick, we had to quit (and continue with intravenous infusions of another drug)."* (13-year-old child, FG)

Another girl described how she felt psychologically tired of taking injections when she lost faith in the effect of the treatment. More examples of quotations on reported experiences of drug effects have been shown in Table 4.

Many children reported decreased pain and joint stiffness and had more energy to attend school and perform normal sports activities. The youngest children had no clear perception of treatment effects, but their parents reported effects based on their observations. Some parents focused on the fact that their child's probability of having a normal life was determined by a positive treatment effect, as symptoms increased during periods of adjustment or during the discontinuation of medications.

> *"This is something we talk to her about – how it might have been without effective medication."* (Parent of 13-year-old child, FG)

Parents reported how they had worked systematically to create secure environments and routines to establish a good relation and cooperation during the procedure of needle injections. Children and parents agreed that children's self-confidence improved over time, as children knew what was going to happen. This building of

Table 4 Children and parents' reports of effects and side effects of the medication

Drug effects	Child's quotation	Parent's quotation
Positive effect	"The medication is very helpful; I'm less stiff, no pain, I'm able to do gymnastics and play handball" (12-year-old child, II)	"I've got a brand new girl! It happened fast, she is very happy and fresh. She felt useless (before). "(Parent of 12-year-old child, II)
Uncertain effect and side effects	"More energy, but not as much as expected. I was nauseous and dizzy" (14-year-old child, II)	"He was better in the body, could perform more, but was nauseous and had a headache" (Parent of 14-year-old child, II)
Effect and side effects	"No" (9-year-old child, II) (she had side effects of steroids)	"The results from blood samples and MR are positive. She is much stronger, she couldn't keep her head straight" (Parent of 9-year-old child, II)
Less effect than expected	"I have had a different effect on different drugs. When having the good effect I could be with friends, join birthday parties and so on …." (15-year-old child, II)	"It was easier when she was younger. It has been hard to find medication for her as an adolescent. She had a period where she didn't want to take the injections – she had lost the faith in the medication." (Parent of 15-year-old child, II)

Abbreviations: *II* Individual interviews positive experiences was described as an important motivational factor.

In some families, only one of the parents performed the injections, either because the other parent did not like needles, or the child did not let them do it, which was illustrated by the following: "*My mum is not allowed to give me the injection, I don't trust her*" (11-year-old child, FG). The father in this situation reported that of the two parents, he had spent the most time building a relationship during the first injections.

Routines and use of coping strategies

In addition to the use of routines and the building of confidence within each family, children and parents described numerous coping strategies to handle needle injections. Children and parents reported a shared experience regarding the establishment of routines and teamwork in the family. A typical example of this has been described in Table 5.

Some children reported that having a friend, sibling, or grandparent present during the procedure decreased fear. They told how bystanders were impressed by their bravery and how they were proud of this. A total of eight children reported that they preferred to do the injections on their own and were aware of the actions necessary to become independent, such as the following participant: "*I said to myself, 'You just have to endure this!'*" (17-year-old child, FG). Only one child, below 13 years, performed the injections herself, but two 12-year old girls claimed they would soon dare to manage the injections themselves.

They agreed that there was less pain when the injection site was in the upper part of the thigh and when the drug was tempered compared to other scenarios. Small children did not have the option to choose between different injection devices, while older children could select drug injections with either syringe or pen. Some preferred syringes, which allowed them to control injection speed, while others favored pens that completed the procedure quickly and in which the needle was invisible.

All families described how they adapted their everyday lives to minimize children's treatment discomfort. Several children went to bed right after the injection, slept longer the following day, ate extra food, and adjusted their school and physical activities. Several children described their strategies in detail.

> "*I drink tea and have a hunger for orange. I get psychological nausea and like to reward myself with some candy, listen to music, or doing something cozy.*" (17-year-old child, FG)

Coping strategies

Most children were familiar with topical anesthesia as a pharmacological tool for pain relief, but only a few reported a significant effect. Thus, most children managed without topical anesthesia. One girl always cooled her skin with an ice cube and considered this her primary strategy. No children recalled specific instructions for non-pharmacological coping strategies. Parents used prior knowledge and their own experiences, and some searched the Internet to find methods of assisting their child. Several useful coping strategies were discovered by chance.

> "*When I was going to have the injection, my favorite series was on the TV, and mom allowed me to watch.*" (9-year-old child, II)

The most commonly used coping strategies have been exemplified in Table 6. All parents offered a wide range of distraction techniques, like looking away, watching television or an iPad, talking about something else, or squeezing their parents' hands. Most children found it helpful to focus on something else. Some reported that having the opportunity to play a video game or watch television was helpful, even when they did not use this option. Others liked to be distracted during the needle stick even if they took part in the preparation.

Most children appreciated getting rewards like toys and chocolate, a nice Band-Aid with a picture on it, or a new sticker to put on a poster every time they received an injection. Children in focus groups had more experience with injections and recalled getting rewards in the beginning. Parents considered rewards a tool to negotiate with their child, and buying a hotdog in the shop at the hospital was a popular reward for completing a procedure. One father said they had used many "bribes" to persuade the child, but had to stop to be fair to the child's siblings. Instead, the child was given the opportunity to choose an activity for the whole family, such as going to a movie, when she had received a specific number of injections.

Table 5 A typical example of routines and teamwork described by one child and parent

Child's quotation	Parent's quotation
"I make everything ready and transfer 0.7 (ml) into another syringe. If there are bubbles, my mum has told me how to shake it away. I don't dare to take the injection alone yet, mummy helps me with the needle stick and I push in the liquid. If I push too fast it's more painful – but then I just take a break before continuing" (12-year-old child, II)	"She cried a little bit the first few times, but I was clear and told her that this is something she has to do. Little by little she has learned her routines, by first preparing the equipment, and then by sitting down and breathing for a while saying; 'I don't like it, but I have to do it' – and then I insert the needle together with her" (Parent of 12-year-old child, II)

Abbreviations: *II* Information from an individual interview

Table 6 Examples from children's and parents' description of commonly used coping strategies

Coping strategies	Children's quotations	Parent's quotations
Distraction	"I often watch TV or iPad or play a game when the injection is prepared" (Several, II)	"We have used a bunch of distraction techniques, like singing, watching movies, soft toys, cold and siblings …." (Several, II and FG)
Rewards	"Toys, chocolate, fun adhesive plaster, poster with stickers, Lego" (Several, II and FG)	"The effect of rewards must not be underestimated" (Parent of 11-year old child, FG)
Control	"I have less control with a pen than a syringe, and I don't appreciate that very much". (16-year-old child, II)	"I think it has been helpful for her to decide something herself" (Parent of 16-year-old child, II)
Relaxation	"When I'm thinking of something I'm looking forward to, I get relaxed" (14-year-old child, FG)	"We practiced breathing techniques in the evenings and a bit yoga, until we felt calm and relaxed" (Parent of 6-year-old child, II)
Increasing knowledge and technical skills	"I think parents should inform their child what is going to happen, and to agree" (15-year-old child, II)	"It is easier when your child understand the reason why she needs the injection" (Parent of 8-year-old child, FG)
Pharmacological Strategies	"I used Emla before, but then I couldn't deal with it anymore" (13-year-old child, FG)	"He doesn't use Emla anymore – it didn't help" (Parent of 14-year-old child, FG)

Abbreviations: *II* Information from an individual interview, *FG* Information from a focus group

Although negotiations and rewards were intended to provide children with control, some parents reported that this behavior delayed the procedure more than it helped the child's coping. Gradually giving the child more responsibility was described as a better way for the child to gain control. Children wanted knowledge of the disease and needed a justification for the injections.

Some parents used metaphors, labeling the drugs the child's best friend in helping them fight the disease. Several children had watched a video that showed a girl playing her favorite sports and living a normal life despite RD. The children found this video very helpful, and it also helped when explaining their disease to their peers. They would like to find similar videos on the Internet, which presented recommendations for the implementation of needle injections.

Continuing with needle injections

Children accepted that they would have to continue with needle injections as long as the treatment improved their quality of life. None had received a recommendation to stop the treatment due to remission of the disease, and children and parents did not know how long the treatment would last. Some hoped to stop the treatment within a few years. Children and parents described a common goal that needle injections should become a natural part of their daily lives. They found it valuable to share their experiences of home injections, which they hoped would help other children, and stated that their experiences with needle injections were important.

Discussion

The main findings of this study were that the children and parents encountered challenges when attempting to incorporate the injection treatment as a natural part of their daily lives. Families used their own resources and cooperated to create routines and introduce coping strategies necessary to continue with the unpleasant needle injections.

Regular injections comprise more than a little needle stick

Short hospital stays are currently the standard for most children with chronic pediatric diseases, as the health care system focuses on self-management outside institutions [20]. However, parents in this study felt overwhelmed by their responsibility for the daily treatment, which included technical and emotional challenges related to the injections. Findings indicated that many families may need additional follow-up sessions and a gradual increase in responsibility before they are capable of taking care of their child's needs during the needle injection procedure at home.

The parents' views on the treatment varied from being optimistic about treatment effectiveness to worries about potential side effects and long-term consequences. Gomez-Ramirez and colleagues found similar mixed positive and negative emotions among parents of children with juvenile idiopathic arthritis (JIA), who they described as being on a rollercoaster ride [29]. Children in the present study rarely described the same emotional ups and downs as those reported by young people with juvenile dermatomyositis [30]. In this study, children may have answered questions about the circumstances of needle injections in a narrow sense, while parents shared their stories about the total situation related to having sick children.

Most children and parents gained increased confidence regarding the needle injections over time. However, home treatment entails risks and challenges, such as parents restraining their child or drugs being handled incorrectly, which may disturb treatment continuation. Our findings indicated that home-administration of needle injections is a vulnerable situation that may require individual follow-up by HPs. This was in line with the findings of two previous qualitative studies [29, 30].

Most children feared pain from the needle sticks, although they reported that it did not hurt much. Pain and fear due to needle sticks are common among children [5] and may result in fear, negative pain memories, and needle phobia lasting into adulthood if poorly managed [9, 31]. Although children who were interviewed seemed to adapt to injections over time, many reported fear just prior to the stick, and a few parents reported that severe needle phobia obstructed the treatment. Needle fear may develop after frightening or painful experiences and is linked to operant and respondent learning processes alongside changed transmission and modulation in the nervous system [9, 18]. Researchers have emphasized that a child's memory of pain from the first needle injection may be more important for future experiences of pain and distress than the pain itself [9, 18]. In this study, some children who participated in the video observation study showed more fear during the first injection [21] than they recalled in the interviews, suggesting that later on, they may have reframed their memories in a positive direction.

Reframing children's pain memories immediately after a procedure may reduce anticipatory fear and can be facilitated by telling children how brave they were and how they have done a good job for their body or by boosting their self-efficacy in terms of coping [31]. Many parents in this study had worked hard to build positive experiences for their child related to the injection procedure. Children's confidence at the time of the interview was developed by initial actions at the hospital and parents' support at home. Children and parents emphasized how routines and mutual trust were essential to build confidence and decrease distress. Routines allowed children to become familiar with equipment and the injection. This approach resembled an exposure-based exercise, as it involved allowing children to play with the equipment, which has been shown to reduce high levels of needle fear [32, 33]. Findings revealed that some children found it easier to perform the procedure with bystanders present, but others had to be alone or trusted only one parent to perform the injection. This suggests a necessity to individualize routines.

Distraction may not be the preferred coping strategy

Children and parents gave detailed information about their coping strategies for handling needle fear. Researchers have recommended distraction as the preferred coping strategy for children during needle procedures [12, 15, 34–36]. In the present study, distraction was found useful in the beginning, especially among the youngest children, as it helped children to focus away from the needle stick. Parents often stated that the effect of distraction was discovered by chance and tried out intuitively rather than in response to explicit advice from HPs. Most research on distraction has been related to needle procedures delivered by HPs in time-limited contexts, such as vaccination clinics or during PVC procedures, which are different from home settings for long-term needle injections treatment. Distraction is easily applied in various contexts, and there is a variety of distraction methods available, including iPads, singing, televisions, looking away, talking to other people, squeezing someone's hand, and the application of something cold. Music, bubbles, medical clowns, virtual reality, sweet-tasting solutions for infants, and devices that produce cold sensations and vibrations (for example, "Buzzy") have been shown to be effective in previous research [13, 37–39]. Computer tablets (iPads, iPods, and smartphones) are popular among children and easy to use.

However, a recent randomized controlled trial of distraction using computer tablets for 41 children aged 4 to 11 years who underwent immunization, found that increased pain and negative emotions were reported in the intervention group [40]. Previous studies have suggested that the effect of distraction is not only explained by the method itself but also by the child's perceptions of control [41, 42]. Children with cystic fibrosis and their parents, reported that taking control was essential in coping with needle procedures, meaning the child had to decide some parts of the procedure [42]. Nurses stated in another qualitative study that the child's feeling of control was the basis for successful use of distraction [41]. In our study, some children stated explicit that they needed to feel in control and did not like distraction, whilst others described how they combined control and distraction. The findings of the present study support previous research, highlighting children's perceptions of control as an important part of non-pharmacological methods. Giving children the opportunity to participate in preparation and implementation of the needle procedure seems to be especially meaningful for children with chronic diseases, who are subjected to many painful procedures.

The provision of adult support through non-procedural talk and humor as a means of distraction, has been shown to be effective in improving children's coping during painful procedures, whilst reassuring comments, criticism, apologies, and entrusting children with too much control may increase distress [43]. Parental coaching requires training of the parents, and children with high levels of fear may also need professional support [44]. Research has shown that parents are often given information and supervision immediately before a procedure takes place, when they are distressed [45]. This may limit a parent's memory of the training, meaning that they may need additional training to feel confident, especially when acting as a coach for their child. In general, parents of children with chronic diseases are at risk of acting too protectively, which may decrease their child's self-efficacy and augment somatic symptoms [46].

Coping strategies must be age-appropriate. For instance, sweet-tasting solutions are highly recommended for infants, but these are found ineffective in school-aged children [13]. Offering sweets during or after injections was relatively common in this study, and children appreciated sweets and other rewards. Many parents expressed critical comments on this practice, because rewards were unfair to siblings and probably delayed the procedure rather than assisting their child's coping. Children, however, reported positive experiences of rewarding themselves by thinking about something pleasant or doing something fun or cozy. Rewards may be an easily available and commonly used coping strategy unless children and parents receive education on other strategies. Research on the use of rewards is sparse compared to research on distraction techniques, but one study found that parents used rewards after almost 90% of immunizations, whilst distraction was offered during 15% [47]. Findings from the present study showed that rewards may not be the best coping strategy in the long-term.

Building confidence in everyday life

Our findings supported the findings of studies that emphasized children's need to participate in health care decision making [35] in settings where needle procedures are repeated over a long period of time. Although most children seemed to adapt to active coping strategies over time, many families strived until they found a suitable and stable strategy. Some parents who participated in focus groups had used physical restraint in the beginning, because they lacked appropriate coping strategies. This confirmed that physical restraint for painful procedures is still in use. HPs continue to believe that getting a procedure done quickly is preferable for the child despite growing evidence of harmful effects, especially when conducted by parents [17, 19]. Parents are often given the role as "helper" for HPs instead of being prepared for the role of comforting and supportive of the child [16].

Holding a child physically during medical procedures may increase pain and distress during the current procedure and in future procedures and is strongly advised against [48]. The fact that physical restraint was not reported in individual interviews may indicate a change in clinical practice and better awareness of this topic. Focusing on adult communication, acknowledging children's fear, and supporting engagement may strengthen the choice of coping strategy and improve children's decisional control [21]. Many families experienced a very brief education during short hospital stays, which gave them insufficient confidence to handle the technical and emotional challenges associated with the injections. They described a need for far more support and follow-up, and they lacked appropriate information about available material on the Internet.

The importance of participation in school and physical education among children with JIA was shown in a recently published longitudinal study [49]. In this study, school absence at the onset of the disease predicted poorer quality of life several years later. Our findings revealed that children made much effort to maintain school attendance. In general, they used weekends for drug administration to diminish the burden of potential side effects, although this strategy might impede social activities. Methotrexate intolerance was highlighted by children in focus groups, and many parents explained how they took precautions to prevent undesired drug effects.

Methotrexate intolerance may be particularly evident among children with JIA [50], and there seems to be a strong positive association between side effects of methotrexate and needle pain [51, 52]. This intolerance was not the main topic in this study, but findings indicated that intolerance played an important role in children's experiences with needle injections. In an interview study of 12 children (aged 6–12 years), the authors concluded that methotrexate treatment was more difficult than other painful procedures and highlighted the importance of strategies and routines to manage medical side effects [53]. In contrast, in the present study, blood tests were reported more painful than subcutaneous injections. One explanation for this distinction may be the firm routines families had established at home. Children did not have to worry about variations in everyday injection procedures, while blood tests could be performed in unpredictable ways.

Strength and limitations

This study had some limitations. First, individual interviews were conducted a relatively short time after injection treatment had begun, and challenges and coping strategies might have been different if participants had a longer experience or if they had been interviewed a second time. However, focus groups provided a robust longitudinal perspective of children's and parents' experiences. Second, families who volunteered for focus groups were generally resourceful with only moderate problems. However, several parents talked freely about their child's fear of needles and the challenges they faced, such as using physical restraint during injection treatment. A strength of the study was that children of different ages and parents were allowed to share their experiences. Finally, gender might have influenced the results, but using this chosen qualitative approach studying gender differences is not suitable.

Conclusion

Children and parents strived to make the home administration of needle injections a natural part of daily living. Parents felt thrown into a huge responsibility and did their best to preserve their child's trust and cooperation during injections. Most of the learning process and the development of self-management took place at home. Fear of needle pain was present among children, even though they reported that the injection caused only slight pain. Children's main wish was to think as little as possible about injections and to participate in normal activities, as healthy children do. Individual facilitation and choice of coping strategy, the creation of firm routines, and taking shared responsibility in families seemed to improve confidence with long-term injections and seemed to be as important as coping strategies themselves. However, confidence depends on several factors and changes over time, as the child grows older. Regular interest, as well as focus and assessment from HPs on how needle injections are handled at home, would probably serve children's and parents' confidence and overall self-management over time.

This study confirmed findings from a previous study [21] that emphasized the importance of the quality of the first training session and the need for follow-up sessions related to needle injections after being discharged from the hospital. The first training session and follow-up session are often performed by nurses alongside a physician consultation. Investigations of nurses' qualifications and organizational preconditions to conduct education and follow-up sessions on needle injections are needed. This study also illustrated the complexity of regular needle injection treatment at home and its difference from painful procedures completed in the health care services. Future research should focus on interventions that support children's and parent's resources and individual needs at home.

Abbreviations

RD: Rheumatic diseases; JIA: Juvenile idiopathic arthritis; II: Individual interview; FG: Focus group; HP: Health care provider

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Authors' contributions
KS contributed to all phases of the project, including the study design, data collection, data analysis, and manuscript preparation. HS and HW contributed substantially to the design and implementation of the study. All authors contributed to the interpretation of the data, and all authors revised and approved the final version of the manuscript.

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Availability of data and materials

The dataset (audiotapes, transcriptions, and notes) have been stored at TSD at the University of Oslo and have not been made publicly available. This is due to the high risk of identification of the participants.

Ethics approval and consent to participate

The study was approved by the South Eastern Regional Committee for Medical and Health Research Ethics in Norway (2016/1749, 2017/2194). According to article 12 of the United Nations Convention on the Rights of the Child, children (0–18 years) have the right to express their views on all matters affecting them [54]. Oral and written consent was obtained from parents and children ≥12 years. Children ≥16 years gave their independent written consent. Children < 12 years gave oral consent. All data were stored in the Services for Sensitive Data Unit (TSD) at the University of Oslo. Results have been presented without individually recognizable data, but quotations have been exposed in terms of the context and age.

Consent for publication

Not applicable.

Competing interests

The authors have declared that they have no competing interests.

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Publisher's Note

Home administration of needle injections for children with rheumatic diseases: A qualitative study on nurses' perception of their educational role

In review: Journal of Pediatric Nursing

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Abstract

Purpose: To explore nurses' perceptions of their educational role, pedagogical competence, and practice in teaching children with rheumatic diseases and their parents to manage subcutaneous injections at home.

Design and methods: In this qualitative study, we used thematic analysis to analyze data from three focus groups with 14 nurses responsible for patient education at one pediatric ward and two outpatient clinics.

Results: We identified three main themes capturing nurses' perceptions of their educational role: *myriad expectations*, *awareness of own competence*, and *facilitation and prioritization of patient education*. Nurses perceived patient education as an expected but challenging duty of their work. They described a lack of pedagogical competence, insecurity in managing parents' and children's fears and worries, and limited organizational structures guiding their educational role. Nurses who worked in outpatient clinics felt freer to individualize education compared to ward nurses.

Conclusions: Nurses perceive their educational role as significant in enabling children and parents to manage subcutaneous injections at home; however, they require pedagogical competence integrated with daily practice to provide high-quality care. Short-term admissions require a different organization of patient education than before.

Practical Implications: Nurses need increased training in communication and management of children's pain and fear during needle injections. Competence development should include opportunities for reflection and guidance in clinical practice. Pediatric specialist nurses at outpatient clinics seem to have better competence to provide individual patient education for these families. The potential advantage of web-based solutions for nurses' patient education is a promising avenue for future research.

Keywords: patient education; home-based needle injections; rheumatic diseases in children; nurses' educational role; qualitative research

Background

Clinical outcomes of children with rheumatic diseases (RDs) have significantly improved due to treatments including biologics and methotrexate (Brunner et al., 2018). Such long-term treatments involve the administration of subcutaneous injections by the children and their parents at home. Thus, patient education for children and parents is called for, and healthcare professionals (HP) must possess pedagogical competence, disease-specific knowledge, along with an understanding of relevant coping strategies, communication skills, and user participation (Svavarsdóttir et al., 2016; Vågan et al., 2016). Pedagogy is the theory and practice of learning, as well as how this process influences and is influenced by the social, political, and psychological development of learners. *Health pedagogy* is a term commonly used for the approach to teaching patients; however, in patient education, nurses also have to assess the patient's ability to acquire, understand, and use health information (Batterham et al., 2016). A key area in patient education is patients' right to participation. This also applies to children; however, it must be adapted to age and stage of development (United Nations Human Rights, 1989). Actively involving children in decision-making processes can improve their understanding and utilization of healthcare professionals' advice (Quaye et al., 2019). For children with chronic conditions, educational interventions may improve their self-management capability (Saxby et al., 2019).

Injection training is an important part of patient education that is often provided in the hospital setting. Nurses teach children and parents injection techniques while at the same time delivering the first injection. However, this procedure encompasses much more than practical accomplishment, as needle injections may be frightening to children (Heden et al., 2020; McLenon & Rogers, 2018; Orenius et al., 2018; Taddio et al., 2012). Attention to emotional factors is therefore of great importance (Birnie et al., 2018; Duff et al., 2012). Children need detailed information to understand the procedure and information about relevant coping strategies (Bray, Appleton, et al., 2019b; Stinson et al., 2012). Parents are often overwhelmed by the responsibility of managing the injection therapy at home (Spiers & Beresford, 2017; Stinson et al., 2012; Sørensen et al., 2021) and need a repertoire of measures to help the child to adhere to the injection treatment. It is challenging for nurses to meet both children's and parents' needs while balancing the need to complete the procedure in a timely manner (Cummings, 2015; Karlsson et al., 2014).

Hildegard Peplau’s middle range theory of interpersonal relations in nursing provides a theoretical foundation that is still relevant for the current shift toward self-management (D’Antonio et al., 2014). Peplau’s theory describes the principles of individual patient care, phases of the nurse-patient relationship, and how nurses’ various roles, such as teacher and counselor, can help patients feel understood and respected (Hagerty et al., 2017; Peplau, 1997). Peplau emphasized that nurses should teach patients to handle their symptoms and challenges at home, described as a “freeing process” (Peplau, 1997). Peplau’s theoretical perspective may still be relevant when reflecting on nurses’ educational role (Hagerty et al., 2017). Though nurses may recognize a need for pedagogical competence, barriers such as skills, workload, motivation, a physician-oriented atmosphere, and insufficient teaching materials may impede competence in this field (Hwang, 2018; Bergh, 2014). Thus, patient education may vary in different parts of the health service.

So far, there has been a lack of research on nurses’ prerequisites for providing patient education to children with RDs during short-term hospital stays. Therefore, the aim of this study was to explore nurses’ perceptions of their educational role, pedagogical competence, and practice in teaching children with RDs and their parents to manage treatment based on subcutaneous injections at home.

Methods and design

This study has a qualitative, explorative design and is part of a larger project that examines the emotional aspects and handling of repeated needle injections among children with RDs, being initiated at the hospital and continuing at home. The present paper reports on nurses’ perceptions of their educational role related to these patients, and we considered focus groups to be an appropriate method. By gathering nurses with similar experiences in small groups, we ensured that the participants could speak honestly (Krueger & Casey, 2015) and reflect together on the topics given to an expanded understanding. The Standards for Reporting Qualitative Research (SRQR) were used to guide the report of this study (O’Brien et al., 2014).

Setting and sampling

The focus groups were carried out in one pediatric ward and two outpatient clinics at two university hospitals in Norway that treat children aged 0–18 years with different pediatric diseases. We used purposive sampling to recruit nurses with experience performing patient education for children and parents at the onset of home administration of an injection-based treatment. Small groups may afford better opportunities to share ideas; however, they must be large enough to provide a diversity of perceptions (Krueger & Casey, 2015). Most nurses in this study provided patient education for children recently diagnosed with RDs, but the outpatient clinics were small, and not all nurses worked explicitly with RDs. Therefore, three nurses were included who mainly educated children with type 1 diabetes and immune deficiency. This inclusion was justified by the argument that they could provide relevant information about the nurses' educational role in other similar patient groups even though the medical treatment of children with RDs includes a different side effect profile. A nurse coordinator who worked on the ward invited nurses with relevant experience to participate in the study, while a local contact person invited nurses at the outpatient clinics to participate.

Participants

The final sample consisted of 14 nurses allocated into three focus groups, one for each unit. Practical considerations prevented one invited nurse from participating. The sample included most of the nurses who provided training in the home administration of injections at the three units at the time. Their experiences provided a broad understanding of nurses' perceptions of their educational role in different contexts. All nurses were females of European ethnicity, as no males or nurses with other ethnic backgrounds worked in these units during the participant recruitment period. Nurses' experience and level of education varied. Four nurses were specialists in pediatric nursing, and another four had undertaken additional education (e.g., in law, pedagogy, or music) after completing their bachelor's degree in nursing. Most nurses had injection training skills with children and their families, and only four nurses had completed less than 10 such training sessions. Table 1 presents more characteristics of the sample.

Table1: Characteristics of the participants and duration of focus groups

Focus groups	**FG1**	**FG2**	**FG3**	**The complete sample**
Participants: number	6	4	4	14
Age: median (range)	29 (24 - 35)	40,5 (35 -64)	59,5 (31- 63)	40,5 (24 - 64)
Years of nursing experience: median (range)	3,5 (1-8)	9,5 (3- 37)	31,5 (7 – 41)	9,5 (1 - 41)
Education: RN/ pediatric nurse /other¶ (number)	4/0/2	1/1/2	1/3/0	6/4/4
Duration of each focus group: minutes	90	80	70	

¶Other education was in law, pedagogy or music

Abbreviations: FG = focus group, RN = registered nurse

Data collection and context

The focus groups were completed in February 2019. To establish a relaxed atmosphere, we offered the participants refreshments in locations without disturbances (Green & Thorogood, 2018; Krueger & Casey, 2015). To generate rich data, the first author (KS) facilitated group discussions in which participants were encouraged to interact (Green & Thorogood, 2018). KS is an experienced pain specialist nurse with a special interest in pain in childhood and has experience in qualitative research. The last author and PI of this project (HW) was the secretary in two of the focus groups. An external nurse fulfilled the role of secretary in the third focus group. Neither the moderator nor the secretaries were employees at the actual units. Topics for discussion in the focus groups covered the following areas: 1) descriptions of their own experiences with patient education, 2) the knowledge and competence nurses need to educate patients, 3) how they expand their competence, 4) their expectations of training sessions with children that need injections at home, 5) their experiences of managing children's pain and fear, 6) their reflections on how patient education may affect how children and parents manage the home administration of injections, and 7) their experiences of challenges during patient education sessions. The focus group discussions were audio recorded, and the secretaries took notes that were reviewed with the moderator immediately after each focus group. Written notes were included in the data material.

Analysis

We analyzed data by following the six phases of Braun and Clarke's thematic analysis (Braun & Clarke, 2006; Terry et al., 2017). To become familiar with the data, KS listened to the audio recordings, transcribed the recordings verbatim, and read written transcriptions several times. The notes from the secretaries were reviewed together with the transcribed text, and initial ideas for coding were composed and discussed with HW. The transcribed text from each focus group was inductively coded and examined for nuances that provided information about the nurses' educational role. The research group discussed codes and ideas for potential themes and reviewed potential themes several times until agreeing upon whether they reflected the coded extracts and the entire data set. Table 2 shows an example of the analytical process for the topic, "How nurses expand their competence." We used fictional names for the nurses when labeling their speech. NVivo 11 software was used to organize the data, track the coding process, compare codes, and review themes. In the analysis and interpretation, we aimed to understand the significance of the discussions in the focus groups, and we have illustrated our findings using verbatim quotations to emphasize certain topics (Green & Thorogood, 2018; Krueger & Casey, 2015). The entire research team participated in the analytical process, reviewed topics, and discussed results in the context of relevant empirical research and theoretical perspectives. All the authors contributed to the composition of the article.

Table 2 approximately here

Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics in Norway (2017/2194) and performed according to the Code of Ethics (World Medical Association, 2013). All participants provided their written informed consent. Data were de-identified and stored in the Services for Sensitive Data Unit at the University of Oslo. Due to the relatively small sample and risk of recognizing participants, the quotations have been kept anonymous, along with some additional information (e.g., whether a quotation represents many or few nurses).

Results

Overall, our findings showed that short-term stays in pediatric wards present challenges in delivering extensive patient education during hospitalization. The nurses perceived the educational role as squeezed between expectations of completing the training session within a short time span. Furthermore, the nurses supposed that most children need a stepwise approach to this procedure, which they initially find intimidating. The organizational conditions in the two outpatient clinics were different from the pediatric ward; however, all nurses described a lack of pedagogical competence, including managing children's fear of needles. We identified three main themes that captured nurses' perceptions of their educational role: myriad expectations, awareness of own competence, and facilitation and prioritization of patient education.

Myriad expectations

Nurses described a tacit but common expectation of completing the first injection and patient education within one session. The focus of the training session was to teach children and parents the injection technique and to handle equipment safely. The nurses agreed that the technical instructions were comprehensive and stated that they lacked the skills necessary to complete patient education for children and parents. Several nurses described expectations like the following, “If you can give injections, it’s really just throwing yourself into it.” Some nurses described a lack of necessary knowledge about the medications and that the equipment for training was different from what children would use at home. Nurses also described that expectations of accommodating children’s emotional expressions were a bit overwhelming. Even the most experienced nurses discussed the challenges of performing patient education alone. They often wished they could work in a team of two nurses, as illustrated by this slightly ironic quotation:

> *You are expected to find the most suitable distraction method for the child and, at the same time, perform a demanding technical injection, comfort anxious parents, and preferably sing along.*

Some nurses perceived that parents expected the nurses to take care of everyone, and instead of presenting themselves as confident in front of children, they felt nervous. Several nurses described this difficulty of accommodating parents’ anxiety and children’s needs simultaneously. Parents’ anxiety could impede nurses’ relationships and communication with children and disrupt the entire training session. A few nurses had experienced situations where they felt compelled to physically restrain a child in order to complete the first injection. The nurses were all aware that children’s experience of their first needle procedure would shape later experiences and that physically restraining a child has the potential to worsen the fear of needles:

> *Children who have experienced being held down during blood sampling will later on be terrified of everything. When two adults have to hold the child down…. After such a procedure, they don’t even dare to measure their saturation or anything else.*

Some of the nurses at the outpatient clinics preferred to teach parents separately, as parents often needed detailed technical information that could frighten children. Nurses working in the ward did not have this option and were concerned about discharging patients after just one training session:

> *I was thinking: oh my god, this is a lot of information—and now they are going to do this on their own—how would that turn out?*

These nurses did not expect to see children for follow-up, and they expressed a lack of time for follow-up consultations.

Awareness of own competence

Nurses struggled to elaborate on what they included in concepts of pedagogical competence and knowledge. Most nurses related competence to experience and defined lack of knowledge as absence of experience rather than inadequate education. They referred to experienced nurses as role models and stated that the experienced nurses had taught them "everything." However, a few observations of patient education by an expert were seen as insufficient preparation to be responsible for the training sessions:

> *I have never had any education in training sessions for needle injections. I did not really know what kind of medicine it was; I could only give subcutaneous injections.*

Nurses agreed that their basic nursing education was inadequate. For example, most nurses said they lacked skills and experience in using specific methods to manage children's pain and fear. They had different views on the use of non-pharmacological measures, and some nurses were in doubt as to whether such measures were effective. Other nurses explained that they believed distraction could help; however, lacking available tools beyond entertainment on mobile phones. More experienced nurses used several distraction techniques, often randomly chosen rather than selected for their effectiveness and individual suitability. Many nurses believed that completing the first injection would help children overcome their fear:

> *Many children are surprised by how little pain there is, but the whole process and imagining the stick and having a needle inside—it's scary.*

Nurses related that this belief could sometimes justify completing an injection even if the child complained. However, several nurses agreed on the importance of creating good memories, encouraging the child to think of what they achieved, instead of reminding them of the times a procedure did not succeed. Some experienced nurses described how they sometimes had to provide a break during the procedure:

> *If the child has rejected for an hour, we will not succeed in persuading the child. By taking a break, the child often regains some control so that we can complete the procedure.*

There were also different views on how nurses' pediatric competence had developed and improved the educational session. A few nurses stated that such skills would probably develop just by working on a pediatric ward, while pediatric nurses' opinions deviated:

> *I know we have another focus during our education: about children's development physically and psychologically—and so—you are more aware of that, I would say.*

Many nurses called for opportunities for discussion and reflection within their daily work and requested access to guidelines on patient education. They also felt a lack of knowledge about research literature on children's pain and fear due to needle procedures but expressed a positive attitude toward local projects aiming to improve clinical practice.

Facilitation and prioritization of patient education

All nurses reported that they usually completed the first injection and patient education either the same day children were discharged or during a follow-up at the outpatient clinic. This spared families unnecessary travel, as they often lived far away from the hospital; however, this did not facilitate the learning process:

> *Some of the children return for follow-ups and report that they do not always succeed with needle injections at home; however, we really want them to manage well.*

The ward nurses pointed out that children with RDs had previously been hospitalized for a long time. Now, most children with RDs were discharged after only a few days, while other children suffering from, e.g., neurological diseases were sicker and needed more extensive nursing care. The nurses often felt squeezed between the many tasks, as exemplified by the following quote:

> *The planning at the ward doesn't provide us sufficient time. The children here are more critically ill, so we have to prioritize their needs before those with rheumatic diseases in need of patient education—right? Previously, these patients were hospitalized for a week, not just two days, especially the newly diagnosed ones; they should have been given repeated information and training in needle injections.*

Attempts to deliver patient education in the afternoon, when wards were less busy, often failed, as nurses felt pressured to discharge patients as soon as possible. The ward nurses also lacked adequate facilities, such as a separate room adapted for educational sessions, meaning that they had to use children's bedrooms or other random, vacant places. However, nurses working in outpatient clinics expressed greater confidence in the implementation of patient education. They could arrange several consultations either by telephone or in person:

> *We have the freedom to set up our own appointments with the family. We try to put together a good plan. If the child needs to receive the injection here a couple of times, then we have to make it happen.*

Most nurses expressed skepticism about leaving injection training to general practitioners (GPs), and several referred to bad cases, such as in the following statement:

> *I remember a boy who was about to change medication and didn't want to have the injection right away. We agreed that he could have the injection at the GP's office, but there everything happened—swish, swish—very fast! Thus, he mentally locked down. However, when he returned and could practice in a slow tempo—that changed the situation.*

All nurses emphasized the personal responsibility they felt to facilitate education for each child and parent and stated that they lacked the necessary support and guidance from their leaders. Although some nurses were able to offer additional training sessions for their patients, the majority described a lack of a systematic approach to patient education.

Discussion

Nurses perceived patient education as their personal responsibility and an important and expected duty of their daily work, albeit lacking sufficient organizational priority. Their ideals of preventing needle fear and providing children with confidence were difficult to achieve because of limited pedagogical competence and insecurity related to managing children's and parents' fears and worries. Patient education for children with RDs and their parents involves the delivery of complex technical instructions and essential emotional support (Sørensen et al., 2020). If nurses lack not only the necessary knowledge and pedagogical competence but also the ability to convey information to children and parents, then there is a risk that patients will not benefit from education (Spiers & Beresford, 2017; Stinson et al., 2012; Vågan et al., 2016). However, nurses are able to deliver patient education by developing their patient-centered communication skills and improving their preparedness for the procedure (Saxby et al., 2019). Nurses in the present study were not fully aware that communication skills and relationships with children and parents were part of their pedagogical competence, while pediatric nurses concluded that they had acquired the necessary competence from their specialist education. One important part of communication and information is the assessment of children and parents' needs. Studies have shown that newly educated nurses frequently lack confidence and preparedness for clinical assessment in general when providing patient education (Sørensen et al., 2020; Taylor et al., 2021).

Nurses’ lack of pedagogical competence

The focus of training sessions was to provide the first injection and to teach the families technical instructions within a limited period. A common notion that applied to most nurses in this study was that children will get used to needle sticks and that the challenge is getting the first one completed. This may be partly true; however, it implies a stepwise approach including shared decision-making and age-appropriate preparation. Such an approach can reduce children’s fear of needles and improve acceptance of injections (Birnie et al., 2018; Kajikawa et al., 2014; Quaye et al., 2019). The use of non-pharmacological measures can help to establish a relationship between nurses and children, which increases the quality of their cooperation during a procedure (Svendsen & Bjørk, 2014). When nurses lack sufficient time for educational sessions, it may be difficult to achieve a collaborative atmosphere with children and parents (Cummings, 2015; Karlsson et al., 2014). Some nurses in this study had been involved in procedures where the child’s distress and reluctance escalated out of control and led to physical restraint in order to achieve completion. Such actions may be justified by a notion that “applying restraint to a child is in the best interest of the child,” (i.e., receiving the prescribed treatment), while ignoring the children’s own experiences of being forced to complete a procedure (Nilsson et al., 2015). Until recently, research on children’s experiences and perceptions of medical procedures has been lacking (Bray et al., 2015), although attention to children’s preferences and participation in healthcare decision-making has been recommended (Koller & Goldman, 2012). Current studies have revealed that children desire detailed pre-procedural information about what is to happen, how it will feel, and what will help them cope and self-regulate the situation (Bray, Appleton, et al., 2019b; Lööf et al., 2019; Smeland et al., 2019).

Although nurses may feel moral distress and guilt when ignoring children’s statutory right to be heard (United Nations Human Rights, 1989), they lack alternative solutions and therefore often continue with persuasion and restraint in order to get the procedure done “as quickly as possible” (Bray, Appleton, et al., 2019a; Svendsen & Bjørk, 2021). However, nurses are aware that they may disrupt the possibilities of developing a trusting and protective relationship with the child by not respecting children’s right to be heard (Quaye et al., 2019).

Some of the pediatric specialist nurses at the outpatient clinics related how they managed the escalating distress by taking a break, leaving the room, and providing the child with a fresh start after a short while. This strategy has similarities with facilitating a "clinical pause," which provides HPs time to listen to the child's wishes and explore alternative coping strategies (Bray, Ford, et al., 2019). Providing clinical pauses or space provides freedom to disclose personal thoughts and feelings and may serve as a coping strategy (Piccolo et al., 2017; Sørensen et al., 2020).

We found extensive but random use of comfort measures in nurses' practice, most often provided by entertainment on mobile phones. However, nurses lacked a selection of age-appropriate aids, and they based their choices mainly on experience rather than relevant research. Many research papers, educational videos, and campaigns have elaborated on procedural pain and fear in children; in particular, the use of distraction has been widely studied (Birnie et al., 2018; McLenon & Rogers, 2018; Orenius et al., 2018; Taddio & McMurtry, 2015). One such campaign is the YouTube video, "It Doesn't Have to Hurt," which provides simple advice to parents and healthcare providers during needle procedures. The video has been widely viewed and strongly accepted by both healthcare providers and parents (Chambers et al., 2020); however, for the nurses in the present study, such knowledge had not been included in their basic training. International and national organizations, such as the Paediatric Rheumatology International Trials Organization (PRINTO) and the Norwegian National Advisory Unit of Rheumatic Diseases in Children and Adolescents (NAKBUR), provide relevant information on their websites aimed at developing competence in the treatment of RDs in children and adolescents. However, our results showed that the nurses were not familiar with these resources, and some of the newly educated nurses lacked disease-specific knowledge. The nurses in our study did not have access to resources like play specialists, music therapists, or clowns, which are sometimes offered to children during medical hospitalization procedures. Our findings supported the recurring problem that evidence-based knowledge does not guide nurses' clinical practice (Kelo et al., 2013; Renolen et al., 2018). As means of empowering patients to improve self-management, nurse collaboration with user organizations or patient support groups may be untapped resources (Keil, 2019). The advantage of web-based solutions, employed in mobile health applications assisted by nurse-led teams, might also be successful in pediatric chronic disease management (Karataş et al.; Stinson et al., 2016).

Organizational and theoretical perspectives of patient education

Previous research has recommended that the facilitation of patient education should be included in organizational priorities (Vågan et al., 2016). The nurses in our study lacked both guidelines and specific expectations from management on how to practice patient education. However, nurses who worked at outpatient clinics felt freer to individualize patient education than those who worked on wards. A Swedish study confirmed that the conditions for patient education vary between healthcare settings and that teaching is usually intertwined in daily nursing activities as tacit knowledge (Bergh et al., 2014). Similar to the results of this study, they concluded that patient education needs to be clarified to a greater degree and more organized at each workplace (Bergh et al., 2014). Our findings indicate that healthcare institutions should take more responsibility in facilitating a systematic approach to patient education. This should not depend on each nurse's sense of responsibility. Organizational structures built on theoretical foundations that stimulate critical thinking, evidence-based care, and clinical introduction programs are potentially vital for nurses' development and ability to fulfill their educational role (Widarsson et al., 2020). Peplau's theory of interpersonal relations in nursing describes different nursing roles and the transformative power of the nurse-patient relationship (D'Antonio et al., 2014; Hagerty et al., 2017; Peplau, 1997). Her theoretical perspective of self-awareness, personal identity, and individuality has gained renewed recognition in the field of patient-centered care and is standard in modern health services (D'Antonio et al., 2014). However, these professional ideals and the nurses' desire to offer a high standard of care to these children and parents are threatened if their ability to deliver patient education is not present. Nurses who provide patient education need sufficient time and comprehensive competence in nursing, didactic, and interpersonal skills (Bergh et al., 2014; Hwang et al., 2018; Saxby et al., 2019). Our results indicate that pediatric specialist nurses at outpatient clinics had more competence and a better ability to provide patient education and follow-up than did nurses who worked in a busy hospital ward. However, nurses would benefit from an organizational structure based on a theoretical foundation like Peplau's theory (D'Antonio et al., 2014). The relationships between organizational structure, nurses' use of research, and pain management outcomes are complex and currently not fully understood (Yamada et al., 2017). Organizational structures affecting nurses' adherence to evidence-based practice (EBP) in hospitals are investigated less often than interpersonal factors; however, a central concern for leaders is how to create room for EBP given their tight resources (Renolen et al., 2020).

Strengthening nurses’ pedagogical competence

Different scientific cultures at universities and clinical wards may partly explain the persistent lack of knowledge among recently qualified nurses (Widarsson et al., 2020). Clinical competence should be regarded as a process in which critical thinking is facilitated among nurses (Wangensteen et al., 2012). Nurses participating in this study developed their competence by accompanying an experienced nurse a few times without support from any guidelines or explicit expectations from their leaders. Role modeling has a long tradition in nursing and despite the development of evidence-based nursing, a belief in “learning by doing” and support from experienced colleagues is reported as important for newly educated nurses (Pascale Blakey & Jackson, 2016). However, in this tradition, there is a risk of nurses acquiring competence in patient education without reflecting on the pedagogical approach or assessment of the patient’s individual needs (Bergh et al., 2014; Peden-McAlpine et al., 2005). Peplau believed that reflection should be mandatory for nurses and that the nurse-patient relationship is important to achieving effective patient education (D’Antonio et al., 2014). The findings of the present study indicate that nurses would appreciate opportunities for discussion and reflection in their daily work to help them become more aware of their educational role.

Limitations and strengths

This study included experiences from nurses working on one ward and in two different outpatient clinics. Our sample included three nurses from outpatient clinics who educated mainly children with type 1 diabetes and immune deficiency, which broadens the scope of the collected data. Their perceptions of patient education were quite similar to those educating children with rheumatic diseases, and their data merely strengthened the results. The relatively low number of participants may be justified by the concept of information power (Malterud et al., 2016), which indicated that the sample held content-rich information relevant for the study. Nurses working on wards were younger and had less experience and education compared with nurses working at outpatient clinics. This might explain some of the variation in our findings.

Implications for practice

Short hospital stays make it challenging to provide comprehensive patient education to children with RDs and their parents while they are hospitalized. Nurses working on pediatric wards need increased training in communication and management of children’s pain and fear during needle injections. Competence development should include the opportunity for reflection and guidance in clinical practice, as well as skill training using simulation. Pediatric specialist nurses at outpatient clinics seem to have better competence in providing individual patient education for patients’ families. Their skills also represent important resources for less-experienced and less-educated nurses. A promising avenue of future research might be the potential advantage of web-based solutions for nurses’ handling of patient education.

Conclusion

This study revealed that nurses perceive as significant their educational role in enabling children and parents to manage home administration of subcutaneous injections. However, there is a need to increase nurses’ child-specific pedagogical competence and to facilitate and integrate this competence through discussions and reflections in daily practice. Short-term stays in pediatric wards represent challenges with respect to delivering extensive patient education and may necessitate better organizational structures for competence building in specialist health services.

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Appendix:

Table 2: Example of the analytical process of the topic: "How nurses expand their competence"

Author statement

Kari Sørensen: Conceptualization, Methodology, Data collection, Software, Writing- Original draft preparation. Helge Skirbekk: Conceptualization, Methodology, Supervision, Validation, Reviewing and Editing. Gunnvald Kvarstein: Supervision, Validation, Reviewing and Editing. Hilde Wøien: Conceptualization, Methodology, Data collection, Supervision, Validation, Reviewing and Editing, Project administration.

Conflict of Interest Statement

All authors have no conflicts of interest to declare.

Table 2: Example of the analytical process of the topic: “How nurses expand their competence”

<table>
<tr><th colspan="3">Phase 1: Excerpt of transcribed text from each of the focus groups ¶</th></tr>
<tr>
<td>Cathrine: I do not know if I had performed this differently if I not was a pediatric nurse.
Judy: But there is a reason for one to choose an education in pediatric nursing…
Claire: Well, it’s probably because you want to become better and so…, yes
Jessie: The technical part and principles of hygiene, syringes and such stuff are from the education, but the handling of the child is not that easy to learn by reading; colleges and role models are important resources. I would also argue; having three kids myself, is a huge advantage! I feel confident.</td>
<td>Meghan: So all that was in a way new to me, for as I said the first times; I can administrate injections, but then it is to teach and, in addition, to teach a child who may not be willing to learn, so I could have wished more training…, but I went along with Peggy a lot, and she’s GOLD! Having so much experience and .., so I have followed her a lot.
Moderator: Yes?
Louise: But the rest of us have worked with children for many years and are pediatric nurses, so we are used to work and relate to children, both in education and the like, yes, learned a little about coping and children of different ages and… like that
Moderator: So you think that is important… education?
Louise: Yes, I think so! At least it helps.
Moderator: Is there something you miss?
Meghan: Yes, I feel that I maybe should have had a little more experience with….children.
Louise: ...and over the years I have participated in courses and such, it is often about the topic coping and .., I have also taken part in courses about pain in children and such. You receive a few drops over the years, even if you do not specifically immerse into this… I feel that both education, courses and experience help - in daily life
Sophie: Yes, it is possible that a nurse without further education in children, can certainly… if she follows an experienced…, yes then it works safely and (speaks hesitantly), but as you say Louise, it helps…
Louise: Yes, I think you become more conscious!</td>
<td>Anne: No, I have never experienced that they (our leaders) say how they want us to provide training for the patient - you perform the task like everything else, try to be pedagogical, to show and explain and so on.
Simone: I participated in an (patient) education immediately after I finished my own training, but I never had any education in training sessions for needle injections. I did not really know what kind of medicine it was; I could only give subcutaneous injection.
Cathy: But I remember I followed you (Anne: Oh yes?) but I have never registered discussions about a written procedure? Does it exist? (laughs) That one should have a certain time and somehow spread it over the stay and ...
Anne: Yes, that was a good question. I remember it was part of the employee training. When you started, you got a written..., at least earlier; I do not know exactly how it is now (laughs). I have not seen anything…</td>
</tr>
<tr><td colspan="3"></td></tr>
<tr><th colspan="3">Phase 2: Initial codes</th></tr>
<tr>
<td>Personal experience and characteristics
Transfer of knowledge
Role models</td>
<td>Personal experience and characteristics
Transfer of knowledge
Role models</td>
<td>Transfer of knowledge
Role models
Random training of nurses</td>
</tr>
</table>

<table>
<tr><td>Education and course
Random training of nurses</td><td>Education and course
Random training of nurses
Conscious about their own knowledge
Reflection and development</td><td>Written guidelines
Pedagogical awareness
Lack of knowledge in different areas
Lack of structure</td></tr>
<tr><td colspan="3"></td></tr>
<tr><td colspan="3">Phase 3 and 4: Collating and interpreting codes into potential themes and reviewing themes</td></tr>
<tr><td>Confidence with personal experience
Learning from each other
The technical topic is learned at school
Handling of the child must be learned by experience
Education for one’s own sake
Ambivalence</td><td>Personal experience and characteristics
Transfer of knowledge
Role models
Education and course
Random training of nurses
Conscious about their own knowledge
Reflection and development</td><td>Transfer of knowledge
Role models
Random training of nurses
Written guidelines
Pedagogical awareness
Lack of knowledge in different areas
Lack of structure</td></tr>
<tr><td colspan="3"></td></tr>
<tr><td colspan="3">Phase 5: Defining the final theme</td></tr>
<tr><td colspan="3">Awareness of own competence</td></tr>
</table>

¶ The names of the nurses are fictional.

Prosedyre for gjennomføring av video-observasjon 10.08.2017

1. Sykepleier i avdelingen kontakter stipendiat om mulig deltager
2. Dersom OK, vil stipendiat på et avtalt tidspunkt snakke med barn og den av foreldre som er tilstede om prosjektet
    a. Gi skriftlig informasjon til foreldre og eget skriv til barnet (og sykepleier dersom dette allerede ikke er gjort) og be mor (om det er hun som er med) informere far (dersom han er hjemme) om prosjektet og forklare at vi også vil trenge hans samtykke.
3. Dersom forelder og barn er villig til å delta:
    a. Avtale tid og sted for gjennomføring av prosedyren – med sykepleier
    b. Stipendiat møter i god tid slik at skriftlig samtykke kan innhentes fra foreldrene (dersom kun en forelder tilstede, kan den andre ettersende sitt samtykke innen 1 uke)
    c. Rigge utstyr:
        i. 2 videokamera (Gopro) – for oversikt over alle deltagere og handlingene som utføres, samt barnets ansiktsuttrykk
        ii. 1 ekstra lydopptaker for backup av lyd
    d. Stipendiat vil være tilstede i rommet – i bakgrunnen – for å ta notater og passe på at utstyret er slått på og slås av når opplæringen er ferdig (evt dersom deltagerne ikke ønsker å bli filmet)
        i. Skal ikke delta i selve prosedyren / opplæringen
4. Etter prosedyre slutt:
    a. Kort samtale med foreldre og barn:
        i. «hvordan var det?»
        ii. Selve prosedyren? (var det vondt, var du redd, hadde du gruet deg…, barn og foreldre)
        iii. At jeg var med og filmet?
        iv. Be om lov til å kontakte om 4 - 6md (telefonnr/mail) for evt intervju
    b. Samtale med sykepleier
        i. Hvordan var det? – selve prosedyren og det å bli filmet?
        ii. Adgang til pasientjournal for å innhente data om diagnose, tidspunkt for diagnose og behandling
        iii. Bakgrunnsopplysninger om utdanning, alder, erfaring
5. Overføring av data:
    a. Med en gang: fra minnekort i kamera til kryptert PC – deretter slettes data fra minnekortet
        i. Backup-lyd fra lydopptaker lagres på samme måte som film
    b. Lastes opp fra kryptert PC til TSD ved å følge egen prosedyre
        i. Filene merkes med deltagernummer, dato og hvilket kamera
    c. Feltnotater skrives på kryptert PC og lastes opp i TSD - lagres i samme mappe som videofilene
6. Skriftlige samtykker, kodelister, og personopplysninger lagres i safe ved Akuttklinikkens forskningsavdeling

Oslo universitetssykehus

INFORMASJONSSKRIV TIL BARN UNDER 12 ÅR:

”Bare et lite stikk”

Undersøkelse med videofilming av barn, foreldre og sykepleiere når barn får medisin gitt med sprøytestikk

HVORFOR BLIR DU SPURT OM Å VÆRE MED?

Du er blant de barn som skal få medisin mot sykdommen din, gjennom sprøytestikk. Vi lurer på hvordan barn og foreldre kan få best mulig opplæring og hjelp på sykehuset første gangen slike sprøyter settes, slik at barn får minst mulig vondt og ikke blir redde for stikkene. Vi vil gjerne lære mer om hvordan vi best mulig kan hjelpe barn med dette. Barn som er mellom 5 og 15 år og som skal begynne med medisin gitt med sprøytestikk vil bli spurt om å være med i dette prosjektet (undersøkelsen).

HVA VIL SKJE DERSOM DU DELTAR?

Dersom du sier ja til å delta, vil du sammen med dine foreldre bli filmet på video mens dere får opplæring den første gangen du skal få sprøyte. Sykepleieren som hjelper dere vil også bli filmet. En annen sykepleier (som også er forsker) vil være tilstede for å sette i gang videokameraene og snakke litt med deg etterpå om hvordan du syntes det gikk. Dette vil ikke ta noe ekstra tid for deg. Sykepleieren vil hjelpe deg slik som er vanlig når barn begynner med medisin gitt som sprøytestikk. En eller begge foreldrene dine vil være sammen med deg. Det vil bli 10-15 barn som blir spurt om å delta i dette prosjektet.

Bare de som er med i forskergruppen vil få se og høre hele video-filmene. Men for at sykepleiere og leger skal lære noe, vil vi gjerne få lov til å vise små klipp fra filmene når vi underviser om sprøytestikk senere. Da vil det ikke være mulig å kjenne igjen ansiktet ditt eller høre den riktige stemmen din. Når vi studerer filmene av deg og alle de andre barna kan vi forstå bedre hva som hjelper barn slik at det blir mindre plagsomt å få sprøytestikk. Det vi finner ut, skal andre sykepleiere og leger få vite når vi skriver om det. Når prosjektet er helt ferdig, blir video-filmen slettet og ingen kan finne ut hvem du er når de leser om prosjektet senere.

HVA VIL SKJE DERSOM DU IKKE DELTAR

Du bestemmer selv, sammen med foreldrene dine, om du vil være med på dette. Foreldrene dine må skrive under på at du vil være med på dette prosjektet. Hvis du har sagt ja er det lov å ombestemme seg senere. Det er bare å si at du ikke vil mer. Du trenger ikke å forklare hvorfor. Du vil få like god hjelp videre på sykehuset.

Hvis du senere finner ut at du ikke vil være med eller har noen spørsmål om prosjektet kan du eller foreldrene dine ringe Kari Sørensen på telefon: 995 69 394

Tusen takk for hjelpen!

Med vennlig hilsen

Kari Sørensen, Sykepleier i Oslo Universitetssykehus og stipendiat (forsker) ved Universitetet i Oslo

og Hilde Wøien, veileder, forsker, Oslo universitetssykehus og ved Universitetet i Oslo

Dette prosjektet støttes av ExtraStiftelsen og Norsk Revmatikerforbund

Oslo universitetssykehus

INFORMASJONSSKRIV TIL BARN/UNGDOM 12-15 ÅR:

«Bare et lite stikk»

Undersøkelse med videofilming av ungdom, foreldre og sykepleier ved sprøyteopplæring

BAKGRUNN OG HENSIKT

Nyere behandling av sykdommer som for eksempel barneleddgikt medfører ofte at medisiner må tas som sprøyter. Ingen er glad i sprøyter, men noen er veldig redde for sprøyter og andre bryr seg lite om det, eller har funnet ut hva de kan gjøre for å takle det. Helsepersonell vil gjerne vite hvordan de kan hjelpe barn og ungdom slik at de ikke blir redde for sprøytestikk og opplever minst mulig smerte og ubehag. Vi lurer på hvordan opplæringen påvirker barn og unges opplevelse når de må ta slike sprøyter over lang tid. Denne studien er første del av et doktorgradsprosjekt i regi av Oslo Universitetssykehus (OUS) og Universitetet i Oslo (UiO).

HVA INNEBÆRER STUDIEN?

Dersom du sier ja til å delta, vil du sammen med foreldrene dine (dersom de er med) bli filmet på video mens dere får opplæring den første gangen du skal få sprøyte. Sykepleieren som hjelper dere vil også bli filmet. Forskeren (som også er sykepleier) vil være tilstede for å starte videokameraene og snakke litt med deg etterpå om hvordan du syntes det gikk. Dette vil ikke ta noe ekstra tid for deg. Sykepleieren vil hjelpe deg slik som er vanlig når ungdom begynner med medisin gitt som sprøytestikk. Du bestemmer selv om foreldrene dine skal være tilstede. I alt 10-15 barn og ungdom (i alderen 5 – 15 år)blir spurt om å være med i dette prosjektet.

Bare de som er med i forskergruppen vil få se og høre hele video-filmene. Men for at sykepleiere og leger skal lære noe, vil vi gjerne få lov til å vise små klipp fra filmene når vi underviser om sprøytestikk senere. Da vil det ikke være mulig å kjenne igjen ansiktet ditt eller høre den riktige stemmen din. Video og lydopptak vil bli slettet senest i 2022. Det vi finner ut skal helsepersonell få vite om når vi skriver om det, men ingen kan finne ut hvem dere er når de leser om prosjektet senere.

MULIGE FORDELER OG ULEMPER

Det kan oppleves ubehagelig å bli filmet, men erfaring fra andre slike studier er at deltagere venner seg fort til kameraene og oppfører seg slik de pleier. Fordelen ved å filme er at vi da kan undersøke nøye hva som foregår i samspillet mellom ungdom, foreldre og sykepleier. Dette kan være viktig for hvordan ungdom opplever seg trygget eller om de føler smerte og ubehag. Fordelen ved å delta i denne studien for deg, er at du bidrar til at helsepersonell på best mulig måte kan hjelpe andre barn og ungdom til å oppleve minst mulig smerte og ubehag i forbindelse med sprøytestikk.

HVA SKJER MED INFORMASJONEN OM DEG?

Det som blir tatt opp med videokamera blir overført til en sikker «lagringsbank» (Tjeneste for Sikker Data lagring) ved Universitetet i Oslo, som bare forskningsgruppen har tilgang til. Du har rett til å se hvilke opplysninger som er registrert om deg og rett til å få rettet opp eventuelle feil i de opplysningene som er registrert. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

FRIVILLIG DELTAKELSE OG MULIGHET TIL Å TREKKE SITT SAMTYKKE

Som ungdom over 12 år kan du bestemme selv om du vil delta i denne studien, men vi ønsker at også foreldrene dine underskriver. Hvis du har sagt ja er det lov å ombestemme seg senere. Det er bare å si at du ikke vil være med. Du trenger ikke å forklare hvorfor, og du vil få like god hjelp videre på sykehuset.

Hvis du senere finner ut at du ikke vil være med eller har noen spørsmål om prosjektet kan du eller foreldrene dine kontakte Kari Sørensen på telefon: 995 69 394 eller mail: kari.sorensen@ous-hf.no

OPPFØLGINGSPROSJEKT

Før du reiser hjem vil vi be om lov til å kontakte deg (dere) igjen om 4- 6 måneder, for å spørre om dere vil delta i en ny undersøkelse. I den neste studien ønsker vi å snakke med (intervjue) flest mulig av de som har deltatt i denne første studien om hvordan sprøytestikkene oppleves når det har gått litt tid. Disse samtalene vil bli gjennomført hjemme hos dere hvis det er ønskelig.

Tusen takk for hjelpen!

Med vennlig hilsen

Kari Sørensen, stipendiat ved UiO/ smertesykepleier ved Avdeling for Smertebehandling, OUS

Hilde Wøien, forskningsleder, sykepleieforsker, OUS og førsteamanuensis ved UiO

Med i forskningsgruppen er også: Gunnvald Kvarstein, professor ved Universitetet i Tromsø og overlege i Avdeling for Smertebehandling, OUS og Helge Skirbekk, sosiolog og forsker, førsteamanuensis ved Lovisenberg Diakonale Høgskole og Universitetet i Oslo

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, [2016/1749/ REK Sør-Øst]. Dette prosjektet er støttet av ExtraStiftelsen Helse og Rehabilitering via Norsk Revmatikerforbund.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato	Deltakers signatur
	Deltakers navn med trykte bokstaver

Som foresatte til_ (Fullt navn) samtykker vi til at hun/han kan delta i prosjektet

Sted og dato	Foresattes signatur
	Foresattes navn med trykte bokstaver

Sted og dato	Foresattes signatur
	Foresattes navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato	Signatur Prosjektleder/stipendiat
	Rolle i prosjektet

Oslo universitetssykehus

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

”Bare et lite stikk”

Smerte og redsel hos barn med revmatisk sykdom (i alderen 5-15 år) som får gjentatte sprøytestikk i behandlingen av sin sykdom

Dette er et spørsmål til dere som foreldre/foresatte sammen med barnet, om å delta i et forskningsprosjekt som har til hensikt å studere samspillet mellom barn og voksne når barnet får sprøytestikk. Det kan hjelpe oss å forstå hvordan sykepleiere og leger best mulig kan hjelpe barn og foreldre slik at barnet opplever minst mulig smerte og redsel i forbindelse med medisinsk behandling som gis med sprøyter. Barn med barneleddgikt blir i økende grad tilbudt slik behandling, uten at vi vet helt hvordan dette oppleves eller hvordan vi best kan forebygge smerter og redsel når slik behandling skal foregå også hjemme over tid. Denne studien er første del av et doktorgradsprosjekt i regi av Oslo Universitetssykehus (OUS) og Universitetet i Oslo (UiO).

HVA INNEBÆRER PROSJEKTET?

Dersom dere sier ja til å delta, vil den av foreldrene som er sammen med barnet bli filmet på video i forbindelse med opplæringen den første gangen barnet skal få sprøyte. Sykepleieren som hjelper dere vil også bli filmet. Forskeren vil også være tilstede for å sette i gang videokameraene og snakke litt med dere etterpå om hvordan denne prosedyren gikk, og hvordan dere syntes det var å bli filmet. Dette vil ikke ta noe ekstra tid for dere.

Bare de som er med i forskergruppen vil få se og høre hele opptakene. Men for at helsepersonell skal lære noe, ønsker vi å ha muligheten til å benytte små klipp fra videopptakene i forbindelse med undervisning og foredrag. På disse klippene vil man ikke kunne se ansiktene deres eller høre de riktige stemmene. Video og lydopptak vil bli slettet senest i 2022. Resultatene vil bli publisert i internasjonalt anerkjente tidsskrift. Ingen kan finne ut hvem dere er når de leser om prosjektet senere eller i publikasjonen.

I prosjektet vil vi innhente og registrere opplysninger om barnet. Dette gjelder diagnose, hvor lenge barnet har hatt sykdommen og hvilken medisin som barnet får. Disse opplysningene vil bli hentet fra journalen.

MULIGE FORDELER OG ULEMPER

Det kan oppleves ubehagelig å bli filmet, men erfaring fra andre slike observasjonsstudier er at deltagere venner seg fort til kameraene og oppfører seg slik de pleier. Fordelen ved å filme er at vi da kan undersøke nøye hva som foregår i samspillet mellom barn, foreldre og sykepleier. Dette samspillet kan være viktig for hvordan barn opplever trygghet eller motsatt, føler smerte og redsel. Når vi i behandlingsteamet vet mer om hva som gir trygghet for barnet i forbindelse med opplæring i sprøytesetting kan andre barn og foreldre få enda bedre hjelp senere. Sykepleieren vil gjøre slik som er vanlig ved opplæring når barnet får sitt første sprøytestikk.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom dere ønsker å delta, undertegner dere samtykkeerklæringen på siste side. Dere kan når som helst og uten å oppgi noen grunn trekke samtykke. Dette vil ikke få konsekvenser for barnets videre behandling. Dersom dere trekker dere fra prosjektet, kan dere kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Barnet vil få muntlig og egen skriftlig informasjon om prosjektet, og dersom de ikke ønsker å delta vil ønsket bli etterkommet. Dersom dere senere ønsker å trekke dere eller har spørsmål til prosjektet, kan dere kontakte Kari Sørensen (stipendiat) på telefon 99569394, eller mail: kari.sorensen@ous-hf.no

HVA SKJER MED INFORMASJONEN OM DERE?

Informasjonen som registreres om dere skal kun brukes slik som beskrevet i hensikten med studien. Dere har rett til innsyn i hvilke opplysninger som er registrert og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter dere til opplysninger gjennom en navneliste. Kode og navneliste vil bli oppbevart separat og med tilgang kun for forskningsleder og stipendiat. Video-opptakene vil bli lagret og oppbevart i sikkerhet i samsvar med retningslinjer for oppbevaring ved Oslo Universitetssykehus. Kun de som er med i forskergruppen vil få se hele filmene.

Forskningsleder og stipendiat har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om dere vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

OPPFØLGINGSPROSJEKT

Før dere reiser hjem vil vi be om lov til å få kontakte dere igjen om 6 måneder, for å spørre om dere vil delta i en ny forskningsstudie. I den neste studien ønsker vi å intervjue flest mulig av de foreldrene og barna som har deltatt i denne studien om hvordan både barnet og foreldrene opplever sprøytestikkene etter 6 måneder. Disse intervjuene vil bli gjennomført hjemme hos dere hvis det er ønskelig.

Tusen takk for hjelpen!

Med vennlig hilsen

Kari Sørensen, stipendiat ved UiO/ smertesykepleier ved Avdeling for Smertebehandling, OUS

Hilde Wøien, forskningsleder, sykepleieforsker, OUS og førsteamanuensis ved UiO

Med i forskningsgruppen er også: Gunnvald Kvarstein, professor ved Universitetet i Tromsø og overlege i Avdeling for Smertebehandling, OUS og Helge Skirbekk, sosiolog og forsker, førsteamanuensis ved Lovisenberg Diakonale Høgskole og Høgskolen i Hedmark

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, [2016/1749/ REK Sør-Øst]. Dette prosjektet er støttet av ExtraStiftelsen Helse og Rehabilitering via Norsk Revmatikerforbund.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Den av foreldrene/foresatte som er tilstede under video-filmingen

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Prosjektet inkluderer barn og ungdom under 16 år, og skal derfor undertegnes av begge foresatte

Som foresatte til_ (Fullt navn) samtykker vi til at hun/han kan delta i prosjektet

Sted og dato

Foresattes signatur

Foresattes navn med trykte bokstaver

Sted og dato

Foresattes signatur

Foresattes navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato

Signatur

Prosjektleder/stipendiat

Rolle i prosjektet

Oslo universitetssykehus

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

”Bare et lite stikk”

Smerte og redsel hos barn med revmatisk sykdom (i alderen 5-15 år) som får gjentatte sprøytestikk i behandlingen av sin sykdom

Dette er et spørsmål til deg som sykepleier om å delta i et forskningsprosjekt som har til hensikt å studere samspillet mellom barn og voksne når barnet får sprøytestikk. Det kan hjelpe oss å forstå hvordan sykepleiere og leger best mulig kan hjelpe barn og foreldre slik at barnet opplever minst mulig smerte og redsel i forbindelse med medisinsk behandling som gis med sprøyter. Barn med barneleddgikt blir i økende grad tilbudt slik behandling, uten at vi vet helt hvordan dette oppleves eller hvordan vi best kan forebygge smerter og redsel når slik behandling skal foregå også hjemme over tid. Denne studien er første del av et doktorgradsprosjekt i regi av Oslo Universitetssykehus og Universitetet i Oslo.

HVA INNEBÆRER PROSJEKTET?

Dersom du sier ja til å delta, vil du som sykepleier bli filmet på video sammen med barn og foreldre i forbindelse med opplæringen den første gangen barnet skal få sprøyte. Forskeren vil også være tilstede for å sette i gang videokameraene og snakke litt med deg etterpå om hvordan denne prosedyren gikk, og hvordan du syntes det var å bli filmet. Dette vil ikke ta noe ekstra tid for deg.

Bare de som er med i forskergruppen vil få se og høre hele opptakene. Men for at helsepersonell skal lære noe, ønsker vi å ha muligheten til å benytte små klipp fra videopptakene i forbindelse med undervisning og foredrag. På disse klippene vil man ikke kunne se ansiktene deres eller høre de riktige stemmene. Video og lydopptak vil bli slettet senest i 2022. Resultatene vil bli publisert i anonymisert form i internasjonalt anerkjente tidsskrift. Ingen kan finne ut hvem dere er når de leser om prosjektet senere eller i publikasjonen.

I dette prosjektet vil vi ikke registrere noen personopplysninger om sykepleierne som deltar.

MULIGE FORDELER OG ULEMPER

Det kan oppleves ubehagelig å bli filmet, men erfaring fra andre slike observasjonsstudier er at deltagere venner seg fort til kameraene og oppfører seg slik de pleier. Fordelen ved å filme er at vi da kan undersøke nøye hva som foregår i samspillet mellom barn, foreldre og sykepleier. Dette samspillet kan være viktig for hvordan barn opplever trygghet eller motsatt, føler smerte og redsel. Når behandlingsteamet vet mer om hva som gir trygghet for barnet i forbindelse med opplæring i sprøytesetting kan andre barn og foreldre få enda bedre hjelp senere. Som sykepleier vil du gjøre slik du pleier under gjennomføring av opplæring og når barnet får sitt første sprøytestikk.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Vi ønsker å få oversikt over de sykepleierne som ikke ønsker å delta i dette prosjektet før oppstart. På den måten vil de slippe ubehaget ved å bli spurt når det er aktuelle pasienter i avdelingen. Vi ber derfor alle sykepleierne om de kan krysse av for ønsket valg om å delta eller ikke, samt undertegne samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få noen konsekvenser for deg. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Kari Sørensen (stipendiat) på telefon 995 69 394, eller mail: kari.sorensen@ous-hf.no

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

De eneste opplysningene som vil bli behandlet om sykepleierne er ditt valg om deltagelse eller ikke. Denne navnelisten vil kun benyttes for å sikre at sykepleiere som ikke ønsker å delta slipper å bli spurt. Den vil ikke knyttes til datamaterialet.

Forskningsleder og stipendiat har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

Tusen takk for hjelpen!

Med vennlig hilsen

Kari Sørensen, stipendiat ved Universitetet i Oslo, spesialsykepleier og master i klinisk sykepleie, Fag- og smertesykepleier, Avdeling for Smertebehandling, Oslo universitetssykehus

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GODKJENNING

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SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

For at vi skal vite at du har fått invitasjon til å delta, ville det være fint om du fyller ut uansett om du samtykker til å delta eller ikke. Da unngår du å få flere forespørsler.

Svarslippen legges i merket kasse på vaktrommet, Barnemedisinsk sengepost 1

SETT RING:

JA jeg er villig til å delta

NEI jeg vil ikke delta

Sted og dato Sykepleiers signatur

Sykepleiers navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato Signatur

Prosjektleder/stipendiat

Rolle i prosjektet

Individuelle intervjuer_barn
Bare et lite stikk

Tema for samtale med barn

Etablere kontakt
Snakke om hverdagslige ting – noe barnet er interessert i.
Tilby barnet å tegne, skrive eller pusle med noe mens vi snakker (dersom de har lyst)
Jeg tror barnet kan fortelle meg noe som er viktig – for at jeg skal huske alt, tar vi opp lyden på båndopptager – hvis det er greit? Fortelle hva som skjer med opptak og innsamlede data.

Sist vi møttes var jo på sykehuset, da hadde du nettopp fått vite at du skulle få medisin gjennom sprøyter. Jeg fikk lov å være med å filme den første gangen, husker du det?

1. Be barnet beskrive hvordan det er å få sprøyter (tegne/snakke)
   Fortelle detaljer om hvordan det foregår, hvem som gjør hva, når det skjer og hvordan det kjennes ut
   Be barnet fortelle om de bruker noen metoder for å tenke på noe annet eller om de synes det er best å følge med
   Snakke om det å grue seg

2. Be barnet fortelle om første gangen de fikk sprøyten på sykehuset
   Hva de husker og hvordan det var
   Snakke om de har tenkt på om det var noe de ønsket skulle vært annerledes
   Spørre om de husker om det gjorde vondt eller om de grudde seg

3. Be barnet å fortelle litt om sykdommen sin og om sprøytene hjelper
   Spørre om det er ting de ikke kan være med på
   Be de fortelle litt om hva slags kontakt de har med sykehus eller lege/sykepleiere og om det er andre ubehagelige eller vonde ting de husker å ha vært med på

4. Til slutt vil jeg gjerne høre om det er noe de har tenkt på kunne vært lurt å vite om sprøyter før man begynner med det

Avslutning:
Oppsummere det jeg har forstått og fått med meg av samtalen. Spørre om barnet er enig i min forståelse og høre om det er noe mer de vil fortelle før jeg skur av båndopptageren.

Fortelle at jeg skal jeg snakke litt med mamma og pappa om det samme, og at barnet da kan få gjøre noe annet de har lyst til.

Takk for at jeg fikk lov å snakke med deg!

Temaguide for intervju av foreldre

Etablere kontakt. Gå igjennom informasjonsskrivet og hensikten med studien. Minne om taushetsplikt og rett til å trekke seg fra studien uten å oppgi årsak. Innhente skriftlig samtykke.

Kan du/dere fortelle litt om hvordan barnet ditt har det nå?
    sykdomsforløp (effekt av behandlingen, symptomer og plager)
    hverdagslivet (hvor mye er barnet på skolen /i barnehagen, med på fritidsaktiviteter, sammen med venner, familie, er dere foreldre i jobb)

Kan du beskrive hvordan det oppleves at barnet ditt trenger regelmessige sprøyter i behandlingen av sykdommen?
    Kan du fortelle hvordan sprøytestikkene foregår? (hvem stikker, hvordan, når, forberedelser)
    Pleier barnet å se på eller liker hun/han å gjøre/tenke på noe annet? I så fall hva?
    Gruer barnet seg? Hva med deg?
    Gjør det vondt for barnet? I så fall mener du det er stikket eller selve medisinen?
    Opplever du at barnet ditt har bivirkninger av medisinen(e)?

Husker du hvordan det var første gangen barnet fikk sprøyten?
    Kan du fortelle litt om det nå? (noe som var bra/noe som ikke var bra)
    Var det noe du mener kunne vært gjort annerledes?

Hva tenker du om at barnet trenger å fortsette med sprøyter for sykdommen?

Er det andre ting barnet ditt har opplevd på sykehus eller hos legen som du tror har vært/er smertefullt?

Hvordan er ditt eget forhold til sprøyter og stikk?

Er det noe annet du vil legge til?

Tusen takk!

Samtale i grupper

Temaguide, 10-13 år

Bli litt kjent (bli-kjent-lek) og fortelle litt om prosjektet

Bli enige om reglene, for eksempel:
- Det som sies i rommet blir tatt opp på lydbånd – men bare forskerne kan høre på
- Ikke fortelle andre om hva vi har snakket om (bare det vi selv har sagt)
- Ikke snakke i munnen på hverandre
-Dere kan gjerne skrive og tegne underveis – dele med hverandre om vi vil
-Vi trenger ikke å bli enige – alle kan ha forskjellige opplevelser

Samtaletema

1. Erfaringer med sprøytestikk
    a. Fortelle om hvor ofte dere får sprøyte og hvor lenge dere har fått sprøyte.

2. Om smerter og det å grue seg
    a. Fortell hvordan det kjennes ut?
    b. Hvor mye gruer dere for sprøyten? Hvor vondt gjør det?

3. Beskriv det som skjer i forbindelse med sprøytestikket
    a. Hva dere gjør før, underveis eller etterpå?
    b. Hva pleier de voksne å gjøre?

4. Fortell om opplæringen

5. Hvordan påvirker sprøytene det dere gjør på skolen, hjemme og fritiden?
    a. Positivt og negativt
    b. Hva tenker dere om å fortsette med sprøyter?

6. Hva trenger barn og ungdom å få vite når de begynner med sprøyter?
    a. Råd til helsepersonell?

Avslutning
Oppsummering

Tusen takk!

Temaguide FG med sykepleiere

Etablere kontakt, servere litt mat og drikke. Presentasjonsrunde. Gå igjennom informasjonsskriv. Minne om taushetsplikt og frivillighet. Innhente skriftlig samtykke.

1. Beskriv en typisk situasjon med sprøyteopplæring til barn og foreldre.
   a. Hvordan foregår det?
   b. Hva er målet med opplæringen?
   c. Forventninger (barn, foreldre, spl)?

2. Beskriv hva dere trenger for å gjennomføre opplæringen
   a. Hvordan fungerer dette i dag – kunne noe vært annerledes?
   b. I hvilken grad får dere formidlet nødvendig informasjon?
   c. Hvor viktig er opplæringen?

3. Fortell om erfaringer dere har fra ulike opplæringssituasjoner
   a. Hvilken kunnskap og forutsetninger trenger dere for å kunne gjøre dette?
   b. Hvordan verdsettes denne funksjonen og hva får dere av veiledning?
   c. Hvordan bidrar opplæringen til at barn og foreldre kan håndtere dette hjemme?

4. Smerte og redsel
   a. Hvordan reagerer barn og foreldre før, under og etter sprøytestikket?
   b. Hvordan tror dere barn opplever å få sprøyter?
   c. Hvordan er det å gi sprøyter til barn?

5. Beskriv hvordan dere ivaretar barnet under opplæringen
   a. Nevn noe som er viktig å snakke med barn og foreldre om
   b. Hvordan håndterer dere barnets følelser?
   c. Nevn noe som kan hjelpe barnet?
   d. Hva gjør dere hvis barnet ikke vil?
   e. Hvilken rolle har dere som spl under opplæringen (og hvilken har foreldrene)?

6. Hvordan bør sprøyteopplæring foregå (i den ideelle verden)?
   a. Hva må til for å kunne få til dette?
   b. Hva trenger barn og foreldre å få vite når de begynner med sprøyter?
   c. Hvordan (er) og bør oppfølgingen være?

7. I forhold til de temaene vi har snakket om nå – hva er bra slik det er nå, hva er vanskelig og hva kan gjøres annerledes?

Sekretæren oppsummerer det hun har forstått og fått med seg av samtalen. Er dere enige i denne forståelsen? Er det noe mer dere vil fortelle før vi skur av båndopptageren?
Be dem huske å fylle ut skjema med opplysninger.

Takke for at de ville stille opp på fokusgruppeintervju!