

EMPIRICAL STUDIES

Exploring reported distress before and pain during needle insertion into a venous access port in children with cancer

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Abstract

Background: Venous access port is commonly used during cancer treatment in children, yet little is known about how children experience such needle insertion procedures.

Aim: To study *distress before* and *pain after* venous access port needle insertion among children and adolescents with cancer. A second aim was to explore associations between their self-report of procedure-related distress and pain with proxy reports by parents and nurses.

Method: The sample included 43 children/adolescents, aged 1–16 years with cancer, treated at two Norwegian university hospitals. The patient, parent(s), and the nurse performing the procedure completed developmentally appropriate 11-point distress and pain scales before and immediately after the venous access port procedure. Data were analysed using descriptive statistics and non-parametric correlations.

Ethical issues: The ethical code of conduct was followed and conformed to the ethical guidelines adopted by the Regional Committee for Medicine and Health Research and the data protector officer at the hospitals.

Results: For the youngest children (1–5 years), the median distress proxy score was 8 (range 0–9) and pain proxy score 4 (range 0–10). Median distress and pain scores for children aged 6–12 years were 3 (range 0–9) and 1 (range 0–10), respectively, and for the adolescents (age 13–16) 0 (range 0–6) and 1 (range 0–5), respectively. Patients' self-reported distress and pain correlated highly with parents' (distress: $\rho = 0.83$, $p < 0.001$, pain: $\rho = 0.92$, $p < 0.001$) and with nurses' proxy ratings (distress: $\rho = 0.89$, $p < 0.001$, pain: $\rho = 0.88$, $p < 0.001$).

Conclusion: There were individual age differences in experienced distress/pain associated with venous access port needle insertion, with a trend for younger children to experience higher levels of distress/ pain than the older children. Children's self-report of distress/ pain concurred with both parental and nurse proxy reports.

KEYWORDS

childhood cancer, distress and pain, nursing, proxy report, self-report, venous access port

INTRODUCTION

Treatment of children with malignant diseases, such as acute lymphoblastic leukemia (ALL) or brain tumors, demands frequent blood samples, infusions, and transfusions, often for an extended period of months or years [1]. To safely administer cytostatic drugs and reduce the number of needle sticks required for blood sampling and cannula insertions, most children are provided with a central venous line (CVL) before starting cancer treatment. The internal type of CVL is a venous access port (VAP) which is placed under the skin, usually on the chest. A needle puncture through the skin must be performed to access the VAP; however, the port gives little disruption to the child's everyday life (i.e. absence of dressing and no external catheters) [2].

Hospitalized children frequently experience pain from treatment and needle-related procedures [3, 4]. Indeed, some children with cancer report the treatment procedures, including VAP-administration, as the most stressful part of the cancer period [5–7]. Due to their developmental level and limited cognitive development, children and adolescents often use behaviour to communicate [8]. For example, common behavioural demonstrations of fear, anxiety, and helplessness in healthcare settings may include aggression, withdrawal, lack of cooperation, and regression [9]. The impact of fear and anxiety relating to medical procedures can persist long after the encounter, influence coping in the situation, and may impact management of future painful or anxiety-provoking medical procedures, such as the VAP punctures [10, 11]. Such emotional responses can delay essential medical treatment, increase the time frame, and reduce patient satisfaction [11]. Furthermore, in pediatric cancer care, it may even be more critical to gain a positive relationship with health care professionals as survivors of childhood cancer experience long-term health risks and late effects from their therapies that may require long-term monitoring and healthcare support [1].

Previous research related to children's experiences of needle insertions into VAPs are scarce, mainly focused on the effect of premedication with topical anaesthesia (EMLA) [12] medication [13] and /or effect of distractions to reduce distress and pain [14]. For example, a Randomized Controlled Trial (RCT) study investigating the effect of a virtual reality distraction during access to the venous port found that it significantly reduced needle-related pain, fear, and anxiety in children and adolescents with cancer [15]. A recent systematic review on the effect of music therapy in the treatment of children with cancer found it especially effective on distress, anxiety, and depression [16]. In addition, a recent clinical guideline on procedure-related pain and distress in children with

cancer strongly recommends using topical anaesthetic and active distractions in all needle procedures [17].

To the best of our knowledge, no previous studies have explicitly explored self-reported experiences from the needle insertion of the VAP devices in children and adolescents with cancer. Therefore, our primary aim was to explore the level of distress before and pain during the needle insertion into the VAP in children and adolescents with newly diagnosed cancer. A secondary aim was to explore the associations between self-report of distress and pain with the proxy observations reported by parents and nurses.

METHODS

Design

This study uses a prospective observational design where we measure distress and pain associated with having a needle insertion into a venous access port (VAP) catheter among children and adolescents with cancer. Such a study design provides an eminent “snapshot” of the distress and pain in the situation but provides no causal information [18].

Participants

The study was conducted for approximately two years at two large paediatric cancer centers in Norway. The study consecutively included eligible children and adolescents at the ward or the outpatient clinic, 1–16 years of age with any diagnosis of cancer who had had a VAP in place for 2–6 months. Each child/adolescent only participated once. We chose this criterion-based purposive data sampling strategy to target a population accustomed to the cancer diagnosis but relatively short VAP experience. Hence, the children and adolescents had become used to the VAP insertions but were not very experienced with the clinical situation.

Measurements

To provide age-appropriate pain assessments to all participants, we used three pain score scales presented in the same questionnaire (Appendix A1 and A2).

1. The Face Legs Arms Cry Consolability (FLACC) for children younger than four years is one of the most widely used behavioural observation pain scales for children too young to self report pain. This scale

consists of five categories, each of which is scored from 0 to 2, providing a total score ranging from 0 to 10 [19, 20]. The FLACC has shown to be reliable and sensitive for procedural pain assessment [21].

2. The Faces Pain Scale-Revised (FPS-R) for children from 4 to 8 years asks the child to point to the face that reflects his/her pain and has demonstrated strong positive correlations with visual analogue scales and the Numeric Rating Scales (NRS) scale [22, 23].
3. The Numeric Rating Scales (NRS) for children over eight years [24] used by the nurses who ask the child how much pain she/he has, using a number from 0 (no pain) to 10 (worst pain possible). Ratings of 3–4 or more on the NRS scale has been found to represent clinically significant pain [25]. Studies have shown high correlations between FLACC and Visual Analogue Scales in observer pain and distress [21], and the FLACC scores are assessed comparable to those of the commonly used 0-to-10 number rating scale [26].

Furthermore, several studies have found an association between distress and pain and that pain measurement scales can be applied to measure both distress and pain [27, 28]. We, therefore, applied a distress scoring based on the pain measures described above. The terms “worry” and “being scared” were used to reflect the thematic, not semantic, meaning of distress in Norwegian. For example, for children over eight years, the item wording was: “On a scale from 0 (I’m not worried at all)–10 (Terribly scared), what are your thoughts about inserting the VAP-needle today?”

In addition to measuring the level of distress and pain, we also collected background information about the child (diagnosis, age), the use of topical anaesthetic’s and/or distraction, and an open question regarding the child’s experience with the procedure, (Appendix A2).

Setting and procedure

Before the VAP needle insertion, the child (older than five years) or adolescent, one of the parents, and the nurse who performed the procedure all completed the first part of their questionnaire, including the level of perceived distress. Then, immediately after the needle insertion, they completed the rest of the questionnaire regarding the child’s experienced/ perceived pain level. Hence, distress was measured before the needle insertion, and pain was measured after the procedure. This order of measurement will be presented throughout the result section.

The nurses provided instructions to the children aged 5–8 years old and asked them to point out the face on the FPS-R scale that best reflected their perceived level

of distress and pain. The nurse or the parent completed the questionnaire on behalf of the child if they were not able or wanted their parents to do so. We intended that the patients, parents, and nurses completed the ratings independently of each other without discussing the ratings. At the end of the questionnaire, the participants had the possibility to write other information as free text if they pleased.

Data analysis

We conducted descriptive statistics and nonparametric Spearman’s rho correlations using SPSS version 21. A *rho*-value close to zero indicates no relationship, while a *rho*-value close to $-/+ 1$ indicates a perfect relationship between the two variables. To provide one proxy score for the youngest children, we used an average of the parent and nurse FLACC assessments. In order to better describe possible variations according to age in the patients’ reported experiences, we divided the patients into three commonly used age groups: the youngest children (1–5 years), school-age (6–12 years), and adolescents (13–16 years) [29].

RESULTS

Sample characteristics

Patient characteristics are provided in Table 1. In brief, the sample consists of 43 (18 females) patients aged 1–16 years, of which 33% were diagnosed with a brain tumor and 27% with ALL. Of the 43 patients, 32 (76%) self reported distress and pain in addition to the proxy scores. The remaining 11 had only proxy-reported distress and pain scores. Except for two of the 24 nurses, all were experienced with VAP needle insertion. The two unexperienced nurses completed the procedure successfully.

Distress scores before and pain scores after the VAP-needle insertion procedure

Fourteen patients (32%) reported no distress before the VAP procedure, and 15 reported no pain (scores 0), while 17 patients (39%) reported scores three and above for distress, and 15 (35%) reported scores three and above for pain. Of these, ten patients (23%) reported high levels of distress and or pain with scores between 7 and 10. The patients’ distress and pain scores related to their age at the procedure are illustrated in Figure 1. Eight children, 17 parents, and 24 nurses provided

TABLE 1 Patient characteristics and procedure-related information

	N (%)	Mean (SD)	Median	Range
Age (years)	43 (100)	9.42(4.39)	10	1–16
1–5	9 (20.9)			
6–12	21(48.8)			
13–16	13 (30.3)			
Time with VAP (months)		3.47(1.28)	3	2–6
Gender - females	18 (42%)			
Diagnostic group				
Brain tumour	14 (33%)			
ALL	12 (27%)			
Lymphoma	7 (16%)			
Other tumours	8 (19%)			
Children from Hospital 1	30 (70%)			
Children from Hospital 2	13 (30%)			
Topical anaesthetics (Emla)	41 (95%)			
1–5 years	9 (100%)			
6–12 years	21 (100%)			
13–16 years	11 (84%)			
Distraction during procedures	14 (33%)			
1–5 years	8 (89%)			
6–12 years	5 (24%)			
13–16 years	2 (15%)			
Distress before VAP				
Child/adolescent distress (N = 32)		2.28 (2.61)	2	0–9
Parent proxy distress (N = 42)		3.17 (2.92)	2	0–9
Nurse proxy distress (N = 41)		3.34 (3.38)	2	0–10
Pain during VAP				
Child/adolescent pain (N = 34)		1.52 (2.12)	1	0–10
Parent proxy pain (N = 41)		2.20 (2.57)	1	0–10
Nurse proxy pain (N = 41)		2.15(2.62)	1	0–10

Abbreviation: ALL, Acute Lymphoblastic Leukemia.

information in the open-ended «Other information» box in the questionnaire. In Table 2, some examples of common comments are presented as illustrative quotes; these comments were primarily descriptive, giving more context to the scorings.

Young children 1–5 years (n = 9)

For the youngest children, the median proxy distress score was 8 (range 0–9), and pain score was 4 (range 0–10). For

five children, the proxy distress scores were reported in the range 7–9, while for one, the distress-and pain-scores were reported as 0 and 1.

Children 6–12 years (n = 21)

For the primary school-aged children, the median distress score was 3 (range 0–9) and pain 1 (range 0–10). Of these, four patients reported no distress and eight reported no pain. Three patients reported high distress scores before

FIGURE 1 Distress and pain scores for the three age groups. Distress (red dots) and pain (blue dots) scores for the children in the three different age groups. The mean distress- score is drawn in red, and the mean pain- score in blue (Self-scores are used except for the youngest children where the mean of the parent and the nurse scores are used (proxy-reported))

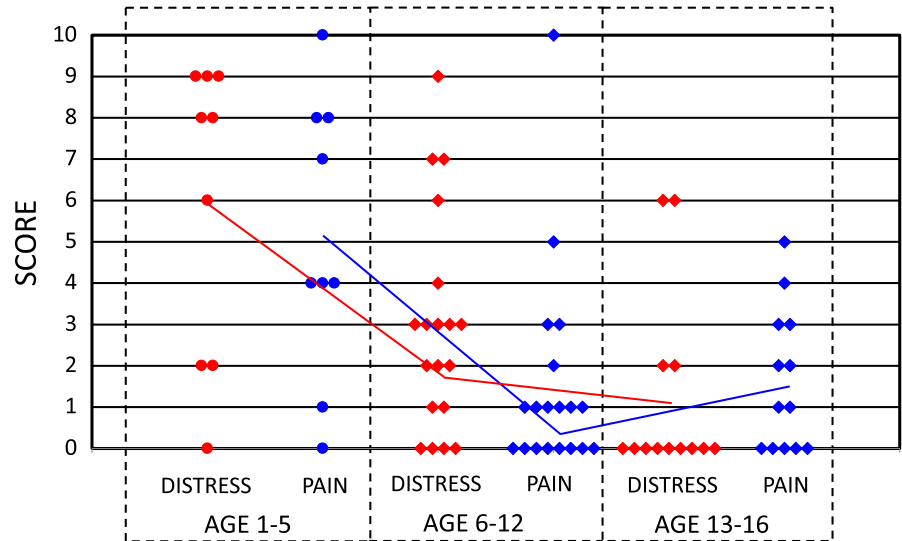


TABLE 2 Illustrative quotes from the nurses and parents in relationship to the distress and pain scores

Age group	Age in years/ Participant ID number	Distress score	Pain score	Examples of positive and negative experiences of the needle insertions into children's VAPs
1–5 years	4 / ID 25	Parent: 8 Nurse:10	Parent:10 Nurse:10	Nurse: "The patient was terribly scared. Screamed from the moment we took off the sweater because he realized what we were going to do. We had to be two to hold him still. It was an unpleasant situation for all of us".
	3 / ID 30	Parent:7 Nurse:9	Parent:3 Nurse: 6	Parent: "Normally, it is unproblematic to insert the needle, but this time she was tired and thirsty."
6–12 years	12 / ID 16	Child: 0 Parent:0 Nurse: 0	Child: 0 Parent: 0 Nurse: 0	Nurse: "Has not had any problems whatsoever when inserting the needle into the VAP. He has got the needle inserted every day over a period of 6 weeks."
	12 / ID 3	Child: 6 Parent: 8 Nurse: 9	Child: 1 Parent: 4 Nurse: 1	Nurse: "The patient was very anxious. Cried and did not want to have the needle insertion. Eventually, she cooperates well."
13–16 years	16 / ID 13	Child: 0 Parent: 0 Nurse: 0	Child: 0 Parent:0 Nurse: 0	Nurse:"The patient seems to be very comfortable concerning his VAP"
	14 / ID 11	Child: 6 Parent: 6 Nurse: 6	Child: 1 Parent: 6 Nurse: 1	Patient: "It is when I see the needle that I feel the fear coming. I had even much more anxiety in the beginning."

the procedure (7–10) but with corresponding pain scores of 0 after the insertion.

Adolescents 13–16 years (n = 13)

For the adolescents, the median distress score was 0 (range 0–6), and median pain score was 1 (range 0–5). The majority (9 of 13) of the adolescents reported no distress, and five reported no pain. Two 14-year-old boys reported distress and pain scores of 4–6.

Only 14 participants (22%) received some form of distraction in preparation for the VAP procedure, and this

was most frequent with the youngest children, where 89% received distraction (see Table 2). 95% of the participants received EMLA as premedication (100% of children <12 years).

Correlations between the patient and proxy rating scores

The patients' self-reported distress correlated highly with both the parents' ($\rho = 0.83$, $p < 0.001$) and the nurses' proxy ratings ($\rho = 0.89$, $p < 0.001$). Likewise, patients' self-reported pain correlated highly with both

parents' ($\rho = 0.92, p < 0.001$) and nurses' proxy ratings ($\rho = 0.88, p < 0.001$).

DISCUSSION

In this exploratory study of 43 children with a VAP, one-third of the patients did not report any distress ($n = 14$) or pain ($n = 15$) related to the needle-insertion procedure, while almost a fourth ($n = 10$) reported high levels of distress or pain. In addition, there was a strong correlation between proxy rating scores and the patients' self-reported scores of distress and pain.

The youngest patients in our study (1–5 years) were perceived to experience higher distress and pain levels than the older patients, even if they more frequently received distraction approaches during the procedures (Table 1). Results from this age group follows the results from other pain studies in children with other medical procedures [30, 31]. For example, in the study of McCarthy et al., VAP needle insertion was reported to be more painful among children younger than 8 years, and 23% showed significant levels of distress with scores higher than seven on the FLACC scale [28].

There can be numerous reasons why we observed a higher level of distress and pain for the youngest compared to the older age groups. Given their immature cognitive skills, the youngest children may not yet have developed the same understanding of the reason for and the importance of their treatment compared to the older children [32]. Our findings are also in line with a recent systematic review stating that generally, needle fear in children and adolescents decreases as age increases [33].

According to a knowledge synthesis on pain from needle procedures [34] the onset of needle fear and phobia is thought to occur between the ages of 5 to 10 years, which makes it crucial to avoid poorly managed needle pain in early childhood. The article claims that such experiences can lead individuals to develop more fearful memories of pain, which may result in an escalating relationship between pain and fear over time.

Many of the school-aged and most of the adolescent patients reported little or no distress and pain. School-aged children can use their cognitive skills to understand the reason for their treatment, and they can use coping methods, for example, distraction intended to reduce the perceived distress and pain [7]. However, some of the older children and adolescents also reported high distress and pain in relation to the needle insertion. Given the ethical and moral obligation of healthcare personnel to avoid unnecessary pain for their young patients [35], being aware of the individual differences across patient ages should encourage clinicians to include children and

adolescents in the decision process of choosing type of CVL. Informed decision is recommended to respect the growing autonomy of children [36,37].

Furthermore, applying engaging non-pharmacological distraction strategies, such as animated cartoons [38], virtual reality [39,40], music therapy [16], or the Buzzy device [41], seems like promising interventions that can be easily applied by nurses in a busy clinical setting to reduce children distress.

Moreover, a recent study [42] investigating the moderating role of parental responses during a painful procedure (lumbar puncture or bone marrow aspiration procedure) in children with cancer found that parental non-pain-attending responses contributed to lower child pain behavior. This result implies that psychosocial interventions that focus on parental emotion regulation may be another key to promote more optimal outcomes in children with cancer undergoing painful medical procedures.

We found high correlations between the parents and the nurses' proxy rating scores and the patients' self-reported scores of distress and pain. Although this suggests that healthcare personnel should be well-positioned to identify patients in need of pain-reducing techniques, other findings on the matter are equivocal. Moadad et al. found that the proxy ratings of the nurses, but not the mothers', were correlated with the ratings of the children [29]. In support of this result, a study among pediatric cancer patients found that parental reports tended to underestimate the children's pain, especially acute pain [43]. However, other studies have found strong correlations between parents' and their children's pain scores [44,45]. Regarding nurses, a study by Khin et al. (2014) on postoperative pain [46] found that the nurses' pain scores correlated poorly with the children's pain scores, whereas children's and parent's pain scores correlated much more closely. Moreover, the nurses scored lower than the children and the parents.

However, the present study supports the notion that both parents' and nurses' ratings of the child's distress and pain during VAP-insertion are in accordance with the experiences of the young patients, indicating that proxy ratings are reliable to use, especially when children cannot verbalize their pain. Maybe our study obtained these results due to the nurses' competence with pain assessment or a trusting relationship between the family and the nurse conducting the VAP procedure. Using a multifaceted approach that considers patient/caregiver report along with the nurses' clinical assessment is critical for effective evaluation and will support interpretation of pain behaviors and initiation of appropriate interventions on behalf of the child or adolescent with cancer [47].

Strengths and limitations

There are several strengths of our study. The consecutive inclusion and participation of patients with various cancer diagnoses spanning a broad age range (1–16 years) and recruitment from two different cancer centers enhance the generalizability. In addition, the procedure we have studied has significant clinical relevance, and the International Association for the Study of Pain (IASP) recommends the applied scales in our questionnaire. Furthermore, we received a self-report for most of the children ($n = 34$), which is considered a gold standard [48].

The study also has a number of limitations: First, we have low statistical power due to a low number of participants; however, all eligible participants agreed to participate during the data collection period. Second, we have not controlled that all completed the ratings independently of each other, which may have contributed to the observed high correlations between patient and proxy ratings of distress and pain. As such, associations between patient and proxy-reported levels of distress and pain should be interpreted with caution. Third, in this study, we have only explored one aspect of having VAP, the needle insertion. It would have strengthened our study if we had explored other aspects of having a VAP for venous access during cancer treatment, such as their satisfaction with having a VAP in periods between treatment and hospitalizations or the incidence and impact of VAP-related infections. Last, we had no possibility to check the nurses' proficiency in assessing pain in relation to the VAP procedure. However, nurses at both sites had received education about the pain assessment tools, and the tools were implemented in their clinical practice.

CONCLUSION

Clinicians should be aware of the individual differences in patients when it comes to experiences of distress and pain related to VAP needle-insertion procedures. This study suggests that parents and nurses are good at perceiving the child's general reactions to potential distress and pain, which must be acknowledged in the decision process for the individual child's preferred type of CVL. This study deals with needle insertion into VAPs only, which is an important piece of the CVL puzzle; however, further research on other aspects of CVL-use that also compares the children's experiences with VAP and external types of CVLs is needed and will fill in the picture further.

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CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest.

AUTHOR CONTRIBUTIONS

SEE, HCL, LK, and ER were involved in the conception and design of the study, SEE and EMW were involved in acquisition of data. HCL, LK, AVM, and MHL analysed and interpreted data and drafted the manuscript in collaboration with SEE. All authors read, revised, and approved the final manuscript.


ETHICAL APPROVAL

The study was approved by the Regional Committee for medical and health research Ethics and the data protector at the participating hospital. All participants gave their informed consent and were assigned a number to ensure anonymity.

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APPENDIX A1



How was your / the child's experience with having the needle inserted into VAP today?

This questionnaire completed on: Date / year: By the child Parent Nurse

Place / Department / :

Child's name:..... Child's age:.....

Vap was operated in, date/year:..... or months ago

You / the child chose which type of catheter to have (VAP or Hickman). Yes No

Before the needle is inserted into the VAP today:

On a scale from 0-10, what are your thoughts about having the VAP-needle inserted today? (worried/scared?).

0 = (I'm not worried at all). 10 = Terribly frightened.

0 1 2 3 4 5 6 7 8 9 10

Complete the rest of the questionnaire *after* you have had the needle inserted into your VAP.

On a scale from 0 – 10, was it painful to have the needle inserted into your VAP today?

0 1 2 3 4 5 6 7 8 9 10

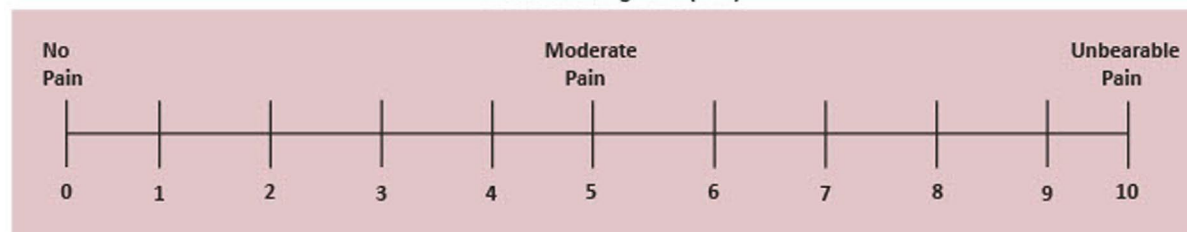
Select the appropriate scale from the following list according to the child's age

For children > 8 years of age, use NRS scale (Numeric Rating Scale).

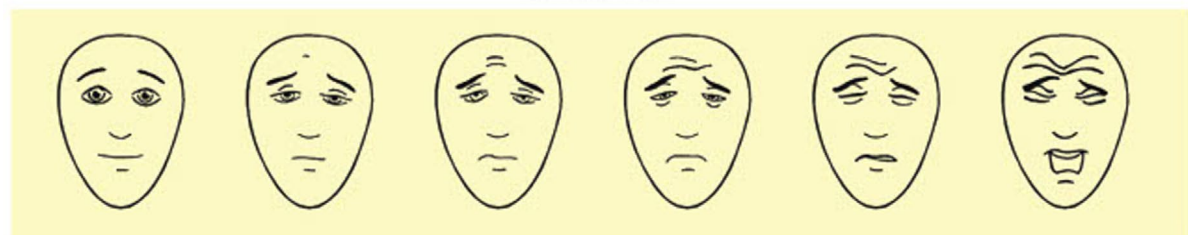
For children (3) 5-8 years of age, use FPS-R scale (Faces Pain Scale –Revised).

For children up to 3 years of age, use FLACC (Face Legs Arms Cry Consolability) scale

Numeric Rating Scale (NRS)



Face Pain Scale



APPENDIX A2

FLACC (Face Legs Arms Cry Concolability)

Kategorier	0 poeng	1 poeng	2 poeng
Ansikt	Ingen spesielle uttrykk eller smil	Av og til grimaser eller rynker pannen, tilbaketrukket, uinteressert	Hyppig til konstant rynke i pannen, stram kjeve, skjelvende hake
Ben	Normal stilling eller avslappet	Urolige, rastlose, ansente	Sparker eller trekker bena opp
Aktivitet	Ligger rolig, normal stilling, beveger seg lett	Vrir seg, flytter seg frem og tilbake, ansent	Bøyd i kroppen, stiv eller rykninger
Gråt	Ingen gråt (våken eller sovende)	Stønner eller klynker, klager av og til	Gråter uavbrutt, skriker eller hulker, klager ofte
Trøstbarhet	Tilfreds, avslappet	Lar seg trøste av berøring, klemmer eller ved å bli snakket med, kan avledes	Vanskelig å trøste eller roe

Did you/the child receive sufficient information/preparation before the procedure today?

Yes No

Did you / the child get premedication / EMLA?

Yes No

If yes, which premedication?

Did you / the child use a distraction method when the needle was inserted into VAP today?

Yes No

If yes, which distraction method was used?

Other information:

The remainder of the questionnaire should be completed by the nurse:

Child's diagnosis: _____

Date of diagnosis: _____

How was the insertion of the needle into VAP performed technically?

Well With difficulty

If with difficulty, do you know why?

Are you experienced with the insertion of a needle into VAP?

Yes No

Other relevant information?

Thank you for your participation!

This questionnaire is made for this VAP study
Submit the completed questionnaire together
with the signed consent to the project nurse
Steinunn E. Egeland

Children's department