

ORIGINAL ARTICLE

Pain in pediatric oncology—A Swedish nationwide follow-up study among nurses and physicians

T. Kamsvåg¹  | J. Arvidson¹ | T. Ek² | L. von Essen³ | G. Ljungman¹

¹Department of Women's and Children's Health, Pediatric Oncology, Uppsala University, Uppsala, Sweden

²Department of Pediatrics, University of Gothenburg, Gothenburg, Sweden

³Department of Women's and Children's Health, Health Care Sciences and e-Health, Uppsala University, Uppsala, Sweden

Correspondence

T. Kamsvåg, Department of Women's and Children's Health, Children's University Hospital, 751 85, Uppsala, Sweden.
Email: tove.kamsvag_magnusson@kbh.uu.se

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Abstract

To examine nurses' and physicians' assessments of pain in children with cancer, and to identify the methods in use to diagnose, evaluate, and treat pain. In addition, to examine whether/how the healthcare professionals' assessment and management of pain has changed compared to 1995 and identify the needs for training. The study has a descriptive and comparative design. 363 nurses and physicians working with children with cancer in Sweden were invited to participate in April 2017. Participants answered an updated version of a questionnaire used in 1995 by Ljungman et al. focusing on the healthcare professionals' experience of pain among their patients, their pain treatment strategies, and need for training. 120 nurses and 65 physicians participated. Fifty percent of nurses and 55% of physicians answered that moderate-to-severe pain was experienced often or very often by children with cancer. Methods recommended in international guidelines to diagnose, evaluate, and treat pain were generally followed. Compared with findings from 1995 by Ljungman et al., nurses, and physicians assessed that moderate-to-severe pain was seen more often. The greatest need for training was reported for pharmacology, different routes for administration of opioids, treatment with nitrous oxide, and nonpharmacological interventions. Nurses and physicians assessed that moderate-to-severe pain is often present in children with cancer. More time to treat pain in the department and training in certain areas seem to be needed to improve pain management.

KEYWORDS

children, health workers, pain, pediatric oncology

1 | INTRODUCTION

Approximately 340 children are diagnosed with cancer in Sweden each year.¹ Pain in children with cancer is categorized as cancer-, procedure-, and treatment-related pain.²⁻⁶ Pain is a common onset symptom in children with cancer, varying depending on localization and severity of the disease.^{7,8} For example, children with leukemia often present with bone and joint pain due

to the infiltration of tumor cells in the bone marrow.⁹ During the treatment, procedure-related pain, for example, caused by lumbar punctures, blood samples, and biopsies, is common.^{10,11} Treatment with chemotherapy, radiotherapy, and surgery has many painful side effects, for example, mucositis, peripheral neuropathy, and postoperative pain.^{2,12} Pain can be evaluated using different methods. Self-estimation tools such as the Visual Analog Scale (VAS) and Numerical Rating Scale (NRS) are often used in older children,

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and facial rating scales can be used in children from approximately 4 years of age.¹³ Proxy ratings using the same scales can be done by healthcare professionals and parents.¹³ In nonverbal children, observational tools focusing on behaviors and physical parameters can be used.¹³ According to children and parents, pain caused by the therapy or procedures is often more distressing for the child than pain caused by the disease itself.^{3,6,8} Pain due to procedures is often more distressing for younger than for older children.^{3,10} The prevalence of moderate-to-severe pain in children with cancer varies between 20% and 80%, depending on diagnosis, time since diagnosis, and type of treatment.^{9,14} Pain interferes with the child's ability to engage in daily activities, keep up with peers and attend school^{15,16} and causes emotional stress for both the child and the parents.^{5,14}

International guidelines for the treatment of pain in children advocate an accurate diagnosis of pain^{12,17} and assessment of pain intensity,¹⁷ proactive pain treatment,^{17,18} and treatment for procedure-related pain.¹⁹ However, studies have shown that pain treatment in children in general, and in children with cancer in particular, is suboptimal.^{6,20-22}

In 1995, Ljungman et al.⁴ conducted a nationwide survey in Sweden among nurses and physicians at 35 departments treating children with cancer. The results showed that nurses and physicians experienced treatment- and procedure-related pain to be a greater problem than pain caused by the tumor. They further showed that instruments to assess pain intensity and type of pain were rarely used. Seventy-two percent of the respondents believed pain could be treated more effectively. Both nurses and physicians requested more time for pain management and training in pain-treating principles in order to optimize pain treatment in children with cancer.

The treatment of pediatric cancer has improved significantly during the last 20 years with more intensive treatment regimens leading to an increase in overall survival,¹ but possibly at the price of more side effects that can be painful. In addition, more treatment is given in outpatient clinics and the children spend more time at home, which means that informal caregivers often are involved in the children's pain treatment.²³ However, concurrent with the development in pediatric oncology, knowledge about pain and pain management has evolved. There are studies showing that the incidence and level of pain in children with cancer is high according to self-assessment, proxy assessment, and observations^{6,8,10} but few studies have evaluated nurses' and physicians' experiences and knowledge of pain in children with cancer.

The primary aim was to examine nurses' and physicians' assessments of the extent and cause of pain in children with cancer in Sweden and to identify the methods in use to diagnose, evaluate, and treat pain. Secondary aims were to examine whether, and if so how, the assessments and management of pain have changed compared to 1995 and to identify healthcare professionals' needs for training in pain management.

2 | METHODS

The study is a survey with a descriptive and comparative design.

2.1 | Participants

Sweden has a population of 10.5 million inhabitants.²⁴ All children with cancer are diagnosed and treated within the public health-care system at one of six pediatric hematology and oncology referral centers. However, shared care is common and some of the treatment of these children is delivered at regional general pediatric departments.

The study was a nationwide survey to all nurses and physicians working at the pediatric hematology and oncology referral centers (Gothenburg, Linköping, Lund, Stockholm, Umeå, and Uppsala) and the nurses and physicians with responsibility for the children treated for cancer at the 25 regional general pediatric departments. In total, 236 nurses and 127 physicians were invited to participate. Of the nurses, 200 worked at a pediatric hematology and oncology referral center and 36 at a regional general pediatric department. Eighty-one physicians worked at a pediatric hematology and oncology referral center and 46 at a regional general pediatric department.

2.2 | Questionnaire

The questionnaire, a modification of Rawal et al.,²⁵ previously used by Ljungman et al.,⁴ was marginally updated by the authors. The questionnaire contained closed-ended questions about the prevalence of pain, treatment principles, common side effects, and need for further education for nurses and physicians. Physicians were additionally asked questions about pharmacological treatment of pain. For every question, 2-5 response options were provided together with an open-ended comment field for some questions, see [Table S1](#). Participants were asked to answer the questions based on their own clinical experiences.

The questionnaire was distributed and answered on a web platform.²⁶ Nurses and physicians were invited to the study by e-mail in April 2017. A reminder was sent by e-mail after 2 and 4 weeks, respectively. E-mail addresses to potential participants were collected by the study coordinator from the pediatric oncology referral centers. All responses were anonymized and could not be traced back to the individual. The Equator Network recommendations were followed, and the authors reported the survey results as suggested by Kelley et al.²⁷ The Regional Ethical Review Board in Uppsala gave approval of the study (Dnr 2016/369), and the Supportive Care Network of the Swedish Pediatric Hematology and Oncology group gave their support to conduct the study.

2.3 | Statistical analyses

Descriptive and explorative statistics were used. Results for continuous variables were described with means and standard deviations (SD), and categorical data were reported with percentages. Since all participants did not respond to all questions, we reported *n* for each question. Potential differences with regard to categorical data were analyzed with Chi-squared test, and potential differences regarding the results between the study by Ljungman et al. and this study were investigated with Fischer's exact test. All tests were performed in SPSS version 27 (IBM). A *p*-value of <0.05 was considered significant.

3 | RESULTS

Out of 363 invited persons, 185 answered the survey, 120 nurses and 65 physicians, which corresponds to 51%, respectively. There was no difference in response rate based on occupation, years of work experience or working at a pediatric hematology and oncology referral centers versus regional general pediatric departments. For a presentation of participants, see Table 1. Some participants did not complete the whole survey, but part of it (45 nurses and 12 physicians).

3.1 | Extent and cause of pain

The nurses' and physicians' estimation of prevalence and cause of pain in children treated for cancer is presented in Table 2. There was no difference between nurses and physicians regarding the perceived prevalence of pain, neither was there any difference based on the number of years of working experience in pediatric oncology or workplace. Treatment-related pain was estimated to be the greatest problem according to 54% of the nurses and 47% of the physicians. Cancer-related pain and procedural-related pain were estimated to be the greatest problem according to 19% and 26% of the nurses and 28% and 22% of the physicians.

If pain persisted despite adequate pain medication, anxiety in the child was seen often/very often according to 87% (*n*=86) of the nurses and 83% (*n*=48) of the physicians. Anxiety in the parents was seen often/very often according to 63% (*n*=62) of the nurses and 81% (*n*=47) of the physicians, and depression in the child was seen often/very often according to 53% (*n*=52) of the nurses and 43% (*n*=25) of the physicians. Most nurses and physicians reported spending 11–20% of their working time treating pain.

3.2 | Pain evaluation

Analysis of pain type (nociceptive somatic/visceral or neuropathic) was performed prior to selecting treatment often or very often according to 36% (*n*=21) of the physicians while 47% (*n*=27) of the physicians responded that analysis of pain was performed if primary treatment did not achieve expected effect. To estimate pain intensity, self-assessment tools were used according to 92% (*n*=91) of the nurses and 98% (*n*=57) of the physicians. Assessment tools and methods are presented in Table 3.

The most commonly used faces scale was the Faces Pain Scale–Revised (FPS-R; used by 56% (*n*=55) of the nurses and 63% (*n*=37) of the physicians), and the most commonly used systematic behavioral observation tool was the Face, Leg, Arms, Cry and Consolability (FLACC) scale (used by 33% (*n*=33) of the nurses and 21% (*n*=12) of the physicians). The majority (96% (*n*=94) of the nurses and 81% (*n*=47) of the physicians) had access to a specialized pain treatment team. Pain consultants were used regularly according to 38% (*n*=22) of the physicians and based on need according to 55% (*n*=32).

3.3 | Pain treatment strategies

3.3.1 | General principles

There were guidelines for pain treatment at the department according to 92% (*n*=141) of the participants and special guidelines on postoperative pain according to 83% (*n*=110). Information about

TABLE 1 Background data of the participants.

Participants, <i>n</i> (%)	Total		Nurses		Physicians	
	185	(100%)	120	(65%)	65	(35%)
Workplace						
Pediatric hematology and oncology referral center	140	(76%)	101	(84%)	39	(60%)
Regional general pediatric department	45	(24%)	19	(16%)	26	(40%)
Professional experience						
<1 year	8	(4%)	8	(6%)	0	(0%)
1–2 years	18	(10%)	15	(13%)	3	(5%)
3–5 years	23	(12%)	15	(13%)	8	(12%)
>5 years	136	(74%)	82	(68%)	54	(83%)

TABLE 2 Extent and cause of pain according to nurses and physicians.

		Nurses n = 100	Physicians n = 60
Moderate-to-intensive pain present	Often/very often	58% (n = 58)	55% (n = 33)
Moderate-to-intensive pain present terminally	Often/very often	75% (n = 75)	78% (n = 47)
More effective treatment possible	Often/very often	52% (n = 52)	58% (n = 35)
Need more time to manage pain	Often/very often	85% (n = 85)	78% (n = 47)
Cancer-related pain present	Often/very often	57% (n = 57)	48% (n = 29)
Procedure-related pain present	Often/very often	72% (n = 72)	62% (n = 37)
Treatment-related pain present	Often/very often	80% (n = 80)	73% (n = 44)

TABLE 3 Assessment tools and methods used to estimate pain according to nurses and physicians.

	Total	Nurses	Physicians
Participants, n	157	99	58
Verbal pain history	95%	96%	93%
Self-assessment tools	94%	92%	98%
Visual analog scale (VAS)			
<7 years ^a	36%	34%	42%
≥7 years	63%	57%	74%
Numerical rating scale (NRS)			
<7 years ^a	13%	15%	9%
≥7 years	27%	27%	26%
Faces scales			
<7 years ^a	64%	61%	72%
≥7 years	26%	34%	12%
Systemic behavioral observation tool	29%	33%	21%
Body image pain chart	24%	16%	28%
Pain diary	28%	18%	45%
Pain questionnaire	8%	9%	5%

^aSelf-assessment of pain can generally not be performed in children below 3–4 years of age.

pain and pain treatment strategies was given to the child and family shortly after diagnosis according to 62% (n = 60) of the nurses and 62% (n = 36) of the physicians.

The most common opioids prescribed by physicians were morphine and oxycodone. Intravenous morphine was prescribed often/very often according to 93% (n = 53) of the physicians, and likewise, oxycodone was prescribed often/very often according to 53% (n = 30) of the physicians. Oral morphine and oxycodone were prescribed often/very often according to 81% (n = 46) and 75% (n = 43) of the physicians, respectively. Patient-controlled analgesia (PCA) was used often/very often according to 46% (n = 26) of the physicians. If the child was treated at home, oral administration of opioids was the preferred route according to most physicians.

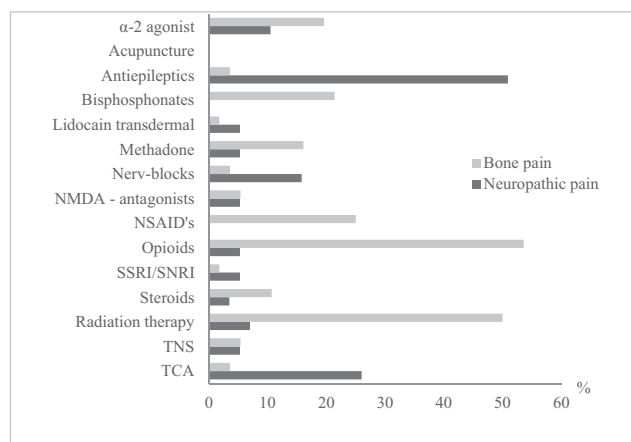


FIGURE 1 Percentage of physicians (n = 57) who considered treatments for neuropathic and bone pain appropriate/very appropriate to use.

Morphine was given "by the clock" according to 79% (n = 45). Additional breakthrough pain doses were prescribed according to 98% (n = 56) of physicians. There was no maximum dose (mg/kg) according to 77% (n = 44) of the physicians. Information about effects and side effects was given to the child/parents before opioids were prescribed to the patient according to 91% (n = 52) of the physicians.

The most common side effect of opioid treatment was constipation, which was seen often/very often according to 61% (n = 46) of the nurses and 64% (n = 35) of the physicians. Sedation was seen often/very often according to 15% (n = 11) of the nurses and 18% (n = 11) of the physicians. Opioid tolerance was seen often or very often according to 20% (n = 15) of the nurses and 18% (n = 10) of the physicians. Psychological addiction and withdrawal symptoms were seen less frequently (often/very often according to 7% (n = 5) and 11% (n = 8) of the nurses and 6% (n = 3) and 6% (n = 3) of the physicians). Laxatives were given often/very often to children on opioid treatment according to 93% (n = 51) of the physicians, and antiemetics were used in combination with opioid treatment often/very often according to 29% (n = 16) of the physicians. The physicians' choice of treatment for neuropathic and bone pain, respectively, is presented in Figure 1.

In the event of anxiety being a part of the child's pain situation, benzodiazepines (88%, $n=50$) or clonidine (95%, $n=54$) were the most commonly used drugs to supplement opioids according to the physicians. Of the physicians, 93% ($n=53$) believed α -2 agonists enhance the effect of opioid analgesia while 37% ($n=21$) believed neuroleptics to do the same.

3.3.2 | Cancer-related pain

For terminally ill children, pain relief was prioritized over reduced consciousness according to 94% ($n=73$) of the nurses and 84% ($n=46$) of the physicians. Likewise, pain relief in this situation was prioritized over respiratory depression according to 82% ($n=64$) of the nurses and 86% ($n=47$) of the physicians.

3.3.3 | Procedure-related pain

Eutectic Mixture of Local Analgesia, lidocaine and prilocaine (EMLA®) and lidocaine-tetracaine (Rapydan®) was used as a routine for venous punctures and insertion of needles in subcutaneous venous ports according to 100% ($n=77$) of the nurses. 99% ($n=76$) of the nurses and 98% ($n=54$) of the physicians answered that general anesthesia was used in >90% of the children undergoing bone marrow aspirations and biopsies. General anesthesia was used in >90% of the children undergoing lumbar punctures according to 86% ($n=66$) of the nurses and 78% ($n=43$) of the physicians. If general anesthesia was not used, EMLA is used according to 84% of the nurses and 94% of the physicians and midazolam or nitrous oxide is used according to 56% and 66% of nurses and physicians, respectively, to reduce pain and distress. Forty-three percent ($n=33$) of the nurses and 42% ($n=23$) of the physicians believed that lumbar puncture without general anesthesia, but with lower grade of sedation, could be as gentle as lumbar puncture done under general anesthesia, provided that adequate analgesia is given.

3.3.4 | Treatment-related pain

Types and occurrence of treatment-related pain according to nurses and physicians are shown in Figure 2.

Laxatives were given very often/often to children on vincristine treatment to prevent constipation, according to 95% ($n=52$) of the physicians and proton pump inhibitors were often/very often given to children receiving high-dose corticosteroids to prevent gastric ulcers, according to 97% ($n=55$) of the physicians.

Information about oral hygiene and oral discomfort during treatment was routinely given to the child and family according to 97% ($n=74$) of the nurses and 91% ($n=48$) of the physicians. Children with oral mucositis often/very often needed parenteral nutrition according to 71% ($n=54$) of the nurses and 62% ($n=33$) of the physicians,

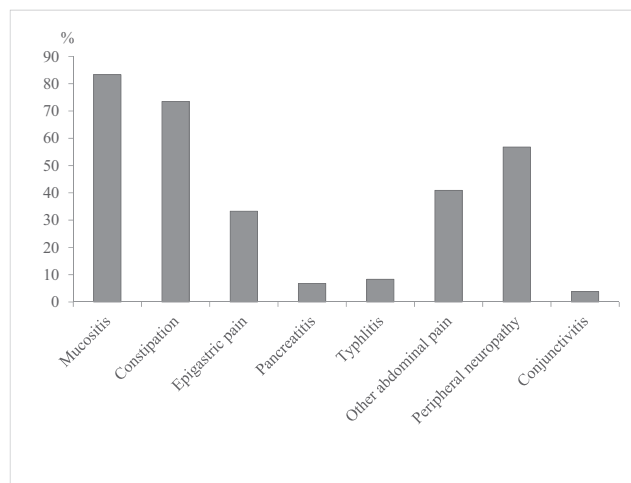


FIGURE 2 Prevalence of side effects of cancer treatment that are seen often or very often according to nurses and physicians ($n=132$).

and 43% ($n=33$) of the nurses and 32% ($n=17$) of the physicians experienced that children often/very often needed inpatient care due to oral mucositis. Lidocaine and benzydamine were the most commonly used local treatments for existing mucositis (used often/very often according to 66% and 74%, respectively, of the physicians). If systemic pain treatment was needed, paracetamol, α -2 agonists and opioids were most frequently used according to physicians (often/very often in 90%, 62%, and 52%, respectively).

3.4 | Comparison with the previous study in 1995

In the study by Ljungman et al. in 1995, one nurse and one physician from each of 35 departments in Sweden, with a special interest in pediatric oncology patients, were included. A comparison of the main findings from this study and the study performed in 1995 by Ljungman et al. is presented in Table S2.

In this study, the number of nurses and physicians reporting that moderate-to-severe pain was present often or very often in children with cancer was higher than in the study from 1995 ($p<0.05$). The proportion of nurses and physicians who believed that more effective pain treatment was possible was however lower ($p<0.05$). The use of pain assessment tools was more frequent compared to in 1995, especially the use of VAS/NRS and faces scales ($p<0.05$), but the use of systematic behavior observations had not changed to the same extent. Access to pain consultants in Swedish pediatric departments has increased remarkably with 90% of the nurses and physicians stating that there are pain consultants available at their hospitals now compared to 10% in 1995. Adjuvant treatment with clonidine was not used in 1995 and the use of neuroleptics as adjuvants for pain treatment, which was more commonly used in 1995, has decreased remarkably. The use of general anesthesia for lumbar punctures has increased since the study by Ljungman et al. ($p<0.05$). Nurses and physicians report that children experience more

treatment-related pain in this study than in the study from 1995, especially for mucositis and constipation/abdominal pain ($p < 0.05$).

3.5 | Need for training

The nurses and physicians expressed a need for training in a variety of fields. Areas where most nurses and physicians expressed a need (moderate to very high) for training were pharmacology of analgesic drugs (94%), analysis of pain type (88%), measurement of pain intensity (83%), tolerance and addiction (83%), and nonpharmacological interventions (82%). Areas where high/very high need for training was expressed differed between nurses and physicians and are presented in Figure 3.

4 | DISCUSSION

In this study, we examined nurses' and physicians' assessment of pain in children with cancer in Sweden. We found that pain was seen often or very often in children treated for cancer, according to 58% of nurses and 55% of the physicians, and treatment-related pain was reported as the most common and distressing type of pain. Similar results have been found in studies on self-reported or parent-reported pain in children treated for cancer.^{6,8,28} In the clinical setting, analysis of pain intensity is well established while analysis of pain type is rare. Among the different self-assessment tools recommended for children, NRS and VAS are recommended for children above 7–8 years of age and faces scales from approximately 4 years

of age depending on the child's cognitive capacity.^{17,29} Our results show that nurses and physicians also report using VAS and NRS for younger children than recommended, indicating that these tools are most likely also used for proxy ratings by parents and clinicians. The use of treatment with paracetamol, opioids, and clonidine reported by the physicians for pain is in line with international guidelines.¹⁷ The use of topical analgesia in combination with different levels of sedation for procedural pain is also recommended in the literature and used according to most nurses and physicians.¹⁹ In Sweden, nitrous oxide is often administered by trained nurses and the fact that the nurses stated nitrous oxide to be one of the highest prioritized areas for training might indicate that it could be used more often. For some children who prefer this, nitrous oxide can be a good alternative with few side effects to general anesthesia for minor procedures.³⁰ However, due to the risk of interactions,³¹ the use of nitrous oxide in lumbar punctures in pediatric oncology is limited since many chemotherapy regimens include intrathecal administration of methotrexate followed by intravenous high-dose methotrexate, which may be potentiated by nitrous oxide.³¹

More nurses and physicians reported that children with cancer experience moderate-to-severe pain. However, there were fewer nurses and physicians who believed that more effective treatment of pain was possible. This result can be interpreted in various ways. One reason could be tight schedules for healthcare professionals in their clinical work.^{32,33} The fact that the majority, especially nurses, reported a need for more time in order to give optimal pain treatment supports this assumption. Another reason could be that most of the supportive care takes place at home with parents having a great responsibility for the care, and pain relief, of the child. Studies by Simons et al.²³ and Fortier et al.³⁴ have shown that pain is common in children with cancer cared for at home and that pharmacological treatment of pain is not optimally given at home.

Treatment-related pain is common according to nurses and physicians. These findings could be explained by the fact that more intense treatment regimens result in more pain but also an increased knowledge and attention to side effects. The knowledge about, and use of, α -2 receptor antagonists (clonidine) has developed since 1995 and as many as 93% of the physicians believed that clonidine enhances the effect of opioids while fewer (36%) believed neuroleptics has the same effect. In contrast, 66% of the physicians believed that neuroleptics enhanced the effect in the first study in 1995. This suggests that pain management is constantly under development with new drugs evolving and old treatments being reevaluated, modified, and sometimes discarded.

Nurses stated a higher overall need for pain training compared with physicians. The knowledge about psychological interventions for pain in children has increased significantly during the last decade, which is probably reflected in the nurses' expressed high need for training in this area.¹⁹ Pain treatment is a teamwork where, in addition to nurses and physicians, also physiotherapists, occupational therapists and psychologists play an important part. Educational efforts are preferably addressed to the entire team but in addition, specific training efforts should be directed to

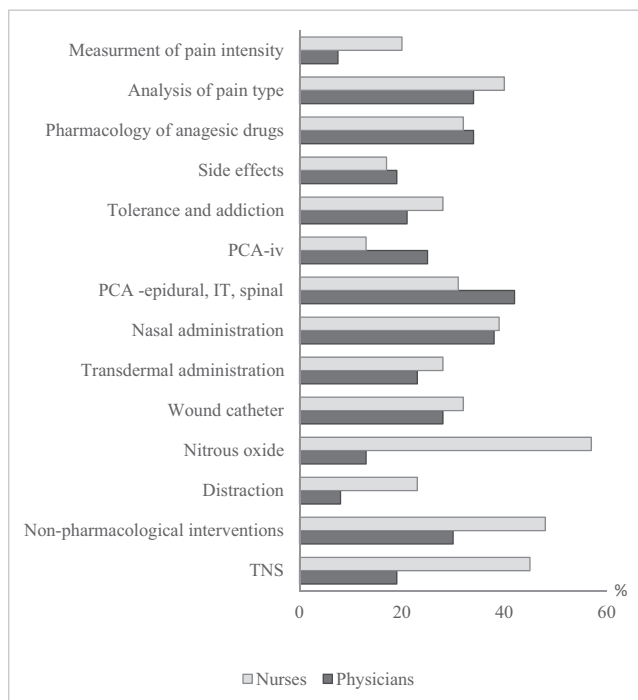


FIGURE 3 Prevalence of nurses and physicians that expressed a high or very high need for training in different areas.

nurses and physicians concerning specific topics such as nurses training in the practical use of nitrous oxide. Compared to 1995, areas where a high need for training were reported, for example, pain intensity assessments and PCA, were reported lower in this study, suggesting that these areas may be well established in clinical practice today.

All nurses and physicians treating children with cancer in Sweden were invited to participate in the study resulting in a variety of clinical experience among the participants. Most treatment for children with cancer is given at the oncology referral centers but supportive and palliative care is also often given at the regional hospitals. Hence, pain in children with cancer is treated in both types of clinics and we therefore chose to include healthcare professionals from all the clinics where children with cancer are treated. Potentially, there could be a difference in the clinical manifestations of pain, depending on if a referral center or local hospital, which could have affected the results. However, there were no differences based on workplace regarding the healthcare professionals' experience of pain in the children they treat implying that any differences are small. The response rate of 51% is in line with other contemporary questionnaire studies, especially among healthcare professionals.^{35,36} There may be a bias in that those who participated are more interested in pain and pain treatment than those who did not participate. We chose to include all responses in the analysis to get a broad perspective of pain and pain treatment strategies. The study presents nurses' and physicians' experiences of pain and pain management in children on treatment for cancer in their departments. This must be considered when interpreting the prevalence and level of pain reported in this study. Most of the questions and response alternatives were the same as in the study by Ljungman et al. from 1995. One could argue that other response alternatives might have been more suitable, for example, numerical rating scales, but in order to be able to compare results from the two studies we chose to change as little as possible in the questionnaires.

Apart from the stated aims of this study, another consideration was to generate hypotheses about current pain and pain management in children with cancer, which through further research, might assist in reducing the suffering caused by pain.

In conclusion, moderate-to-severe pain was reported often/very often in children with cancer according to 58% of the nurses and 55% of the physicians. Methods recommended in international guidelines to diagnose, evaluate, and treat pain were generally followed. In comparison with the study in 1995, pain intensity assessments, patient-controlled analgesia, and clonidine were areas where the use has increased the most. More time to treat and prevent pain and training in certain areas seem to be needed to achieve improved pain management.

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ORCID

T. Kamsvåg  <https://orcid.org/0000-0003-2696-4054>

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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