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Pain in Pediatric Oncology: Do the Experiences of Children and Parents Differ from Those of Nurses and Physicians?

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ABSTRACT

Diagnosis and treatment of pain are central components in the care of children with cancer. The aim of the present study was to compare the viewpoints of children and parents with those of professionals, on different aspects of pain in children with cancer. Information was collected through questionnaires and interviews. In particular, we focused on the extent and causes of pain, strategies to reduce procedural pain, pain evaluation, and attitudes to pain treatment.

We found that both families and professionals shared the opinion that pain was a common symptom during different phases of cancer treatment but, surprisingly, professionals regarded it as more frequent than families. The groups agreed that treatment related pain is the most critical problem, followed by procedure and cancer related pain. Concerning strategies to decrease procedural pain, there was a high concordance in views between groups. Nurses and physicians more often claimed that failing pain treatment was associated with psychological factors such as high levels of anxiety in parents and children, loneliness, and lack of preparation. The self-report, according to both parents and professionals, is a feasible procedure even in young children from 4 years of age. Both groups asserted that parents were better in ascertaining the extent of their child's pain.

In conclusion, although the families and professionals in this study have many comparable views concerning pain in children with cancer, divergences also exist. To acquire a more accurate picture of the situation we must focus on the views of the children first, and then those of parents and professionals. A tendency to overestimate the problems was observed in professionals. Hopefully this reflects a keen awareness of the current situation.

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INTRODUCTION

Although there have been improvements in pain treatment in the last decades, pain and underestimation of pain are still common problems in pediatric oncology (1-6). It has also been shown that fear of pain is a major concern of children with cancer (7,8).

Different studies concerning pain assessment have compared the perspectives of children, parents and medical professionals (9-14). Sometimes discrepancies between perspectives have been shown. A proposed reason for this has been inaccuracy in measurement (10,12). When a child's rating does not agree with an observer's rating, it has often been concluded that the child is providing an inaccurate assessment (14), or is unable to understand the required task. When the parent's rating show discrepancies compared to that of a trained observer, it has been presumed that the parents are biased (15). It has been suggested that each mode of assessment may target a different aspect of pediatric pain, and that it may be more useful to understand the factors that contribute to differences among ratings, rather than to outrule data obtained from a certain individual (11,13).

Previously, problems in pain diagnostics and management have often been investigated from the perspective of medical professionals. In analogy with the discussion on assessment of pain, we consider it important to describe the current pain problems in pediatric oncology from different perspectives so as to form a truer picture of the situation.

In a previous publication (4), we presented the views of nurses and physicians in Sweden on the prevalence of pain in children with cancer and problems associated with pain evaluation and pain treatment. In a follow-up investigation (5), we summarized children's and parents' responses to the same questions. The comparison of these experiences from different perspectives is so important and extensive that we chose to present it as a separate article. This also gave an opportunity to add a minor questionnaire study to make the comparison more complete.

The aim of the present study was to compare the viewpoints of children and parents with those of professionals, on different aspects of pain in children with cancer. In particular, we focused on the extent and causes of pain, strategies to reduce procedural pain, pain evaluation, and attitudes to pain treatment.

MATERIALS AND METHODS

Nurses and physicians

1. The views of nurses and physicians on different aspects of pain in children with cancer were investigated through a nationwide survey using postal questionnaires. The results and details of the questionnaire have been published (4). Of the 47 pediatric departments in Sweden, 35 take an active role in the treatment of children with cancer. One physician and one nurse from each of these 35 departments responded (response rate 100%).

2. Furthermore, a minor complementary questionnaire survey was conducted to investigate the views of medical professionals, at the tertiary care pediatric oncology unit in Uppsala, with respect to 10 questions on pain evaluation. In total 25 responses were obtained; 3 physicians and 22 nurses (response rate 83%). This latter questionnaire was designed to allow a comparison with the views of children and parents on the same issues.

Children and parents

The experiences of children and parents were investigated in an interview study (5). All children admitted during a six-month period to the pediatric oncology ward in Uppsala, and their parents, were invited to participate in the interview study. For inclusion, the child had to be in the treatment period from one month after diagnosis to three months post-treatment. Sixty-six children and their families met the inclusion criteria and interviews were made with 55 (83%) of them. Children under the age of 10 years were interviewed concurrently with their parents, though it was made clear that we primarily were interested in the views of the children. For children 10 years and older, interviews were conducted separately. In this way, we intended to obtain two different views of the same problem for comparison. All the answers from children were compared with those from parents. If significant differences were absent; data are presented as overall percentage scores reflecting the answers of both children and parents (children<10 years) and children (from 10 years) together. We found that the views of children and parents generally were comparable. Therefore, it was appropriate to combine the attitudes of children and their parents and compare them with the attitudes of professionals. Informed consent was obtained from children and parents and the local research ethics committee approved the study.

The statistical differences were analyzed with χ^2-test for non-parametric data and Student's t test for parametric data. The significance level was set at $p<.05$.

RESULTS

Extent and causes of pain

As shown in Figure 1, intensive pain during the last 3 months was seen either often or very often in approximately 5% according to both families and professionals. About 12% of the families as opposed to 40% of the nurses and physicians believed that, in spite of treatment, moderate or intensive pain occurs often to very often. The difference between the groups was greatest when they were asked whether more effective treatment was possible.

The groups were similar as to the prime cause of pain, with treatment related pain being the dominant cause followed by procedure related and cancer related pain (Figure 2).

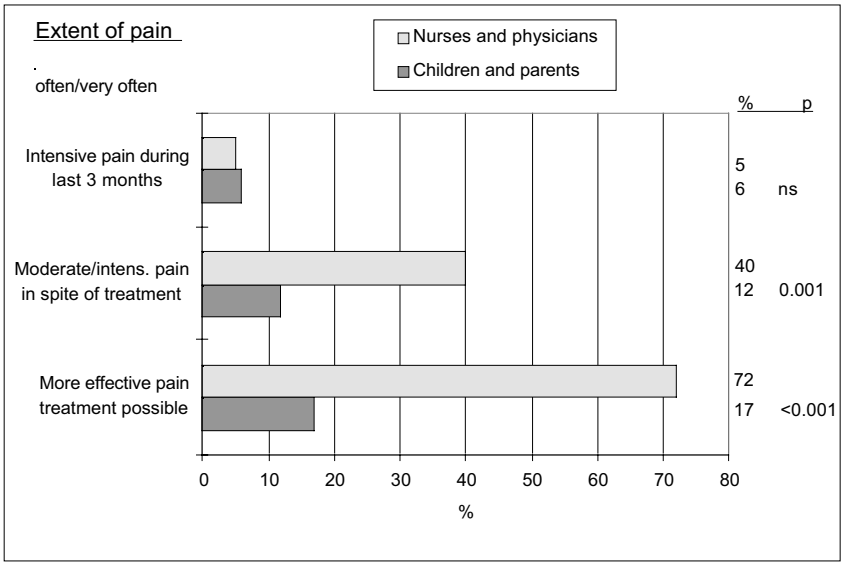

Figure 1. Extent of pain. Percent responses of children and parents (n=55) and nurses and physicians (n=70) regarding the extent and causes of pain.

Strategies to reduce procedural pain

The reports from families and professionals on procedural strategies were highly similar (Table 1). EMLA " (Eutectic Mixture of Local Anesthetics, Astra, Södertälje, Sweden) was usually used before venipuncture/cannulation of a vein and before introducing a needle in a subcutaneously implanted intravenous port. General anesthesia was used in

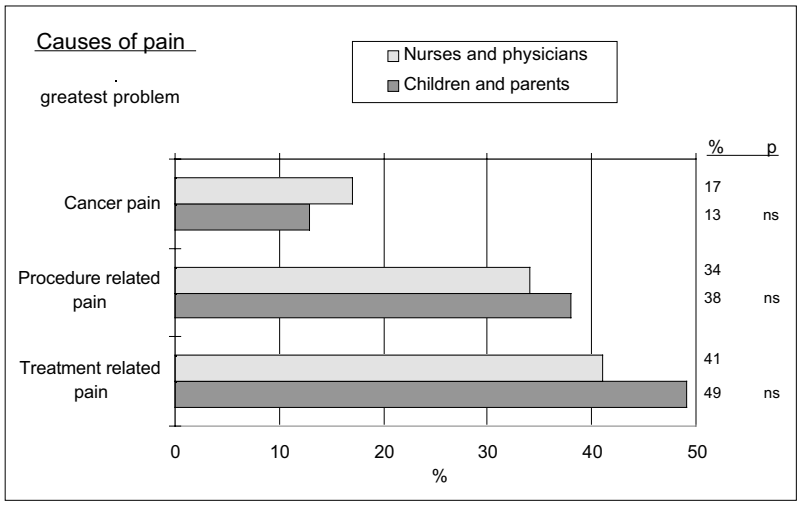

Figure 2. Causes of pain. Percent children and parents (n=55) and nurses and physicians (n=70)giving the following answers concerning which cause of pain is the greatest problem.

approximately half of the children when performing a lumbar puncture and conscious sedation in the other half.

Before performing a lumbar puncture in conscious sedation, EMLA was used very

Table 1. Procedure strategies. Percent children and parents(c) (n=55) stating the presence of strategies compared with nurses and physicians (n+p) (n=70).

	% c	% n+p
EMLA before venipuncture	98	100
Sedation before venipuncture	19	-
EMLA before introducing a needle in an iv port	96	89
Sedation before introducing a needle in an iv port	7	-
General anesthesia in LP (lumbar puncture)	46	50
Sedation in LP	54	50
EMLA before LP	82	94
Sc injection of analgesics before LP	67	59
General anesthesia in BMA (bone marrow aspiration)	86	84
General anesthesia in BMB (bone marrow biopsy)	98	91

often, and in two thirds of the cases an additional s.c. injection of local anesthetics was given. Bone marrow aspirations and biopsies were usually performed with the child under general anesthesia.

There were differences in views of families and professionals on various psychological explanations of inadequate pain treatment. Generally, professionals estimated the impor-

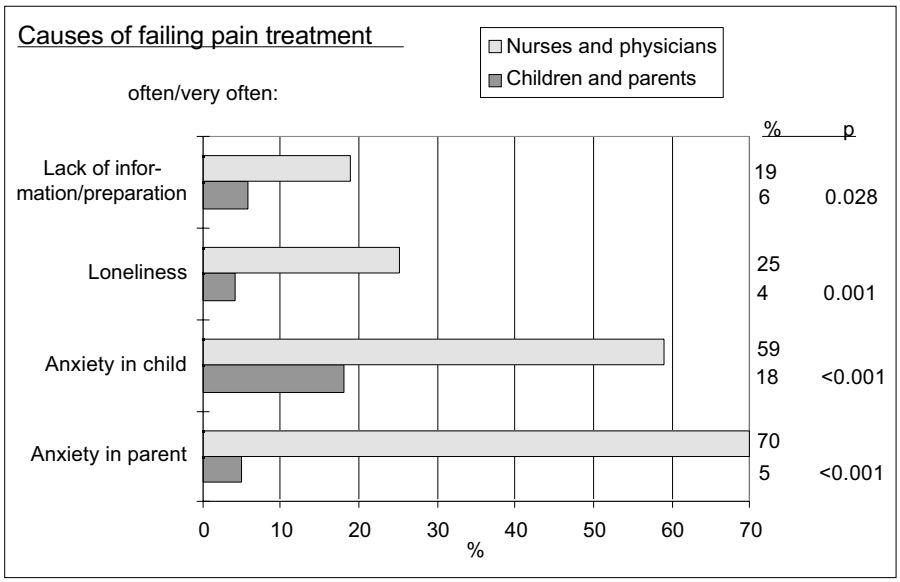

Figure 3. Explanations of failing pain treatment. The views of families (n=55) and professionals (n=70) on different psychological explanations of failing pain treatment.

tance of anxiety in parents and children, loneliness, and lack of information/preparation higher than did children and parents (Figure 3).

Pain evaluation

A high degree of accord exists between parents and professionals as to pain evaluation (Table 2). Parents argued that a child can accurately give self-reports already from 3-4 years of age (mean ± 95% confidence interval; 3.5 ± 0.4). This belief on the part of parents found strong support from nurses and physicians (mean ± 95% confidence interval; 4.27 ± 0.45).

Table 2. Views on pain evaluation. Parents (p) expressing agreement to statements (for all children (n=54), and for children <5 years (n=19) compared with children ≥5 years (n=35) compared with nurses and physicians (n+p) (n=25). * = p< .05

	often / very often correct			
	% p	%n+p	% <5yrs	% ≥5yrs
1. To evaluate how much pain a child has, I get the most important information through:				
a) asking how much pain there is.	68	67	31	84*
b) observing the behavior of the child.	81	88	90	77
2. I think that parents are better to judge how much pain their child has than nurses and physicians.	72	64	84	65
3. I find it difficult to know:				
a) when a child is in pain.		15 16		21 12
b) how much pain a child has (when in pain).	48	44	63	40
4. I think that the pain evaluation routines are such that effective pain treatment can be provided.	83	88	74	89

Attitudes on pain treatment

According to children and parents, opioids were never refused for fear of addiction. In contrast, 42% of professionals claimed that children occasionally refused the use of opioid analgesics for fear of addiction and 2% stated that refusal occurred often. In the group of professionals, 17% claimed that opioids were sometimes refused because patients' relatives were skeptical, but no one in this group said that relatives refusal occurred often or very often.

DISCUSSION

Previously problems in pain diagnostics and management have often been investigated from the perspective of medical professionals. In this paper we describe the pain problems in pediatric oncology from different perspectives; children's and parents' views are compared with those of health professionals so as to form a more complete picture of the situation.

We found that both families and professionals shared the viewpoint that pain was a common symptom during different phases of cancer treatment, but professionals considered it even more common. The groups agreed that treatment related pain was the greatest problem, followed by procedure and cancer related pain. Concer-

ning strategies to reduce procedural pain, no difference was observed between groups. Nurses and physicians more often claimed that inadequate pain treatment was related to such psychological factors as high levels of anxiety in parents and children, loneliness, and lack of preparation. The use of the self-report technique, according to both parents and professionals, is possible in children from the age of 4 years. Moreover, both groups suggested that parents were better in determining the pain intensity their child was experiencing.

A potential problem is that we, in most questions, compare the views of children and parents in one region of Sweden with experiences of nurses and physicians from the whole country. However, according to a previous national study (4), principles of pain management do not vary much in different regions of the country

Many of the questions administered to professionals were used in an earlier study (16) and were tested in a pilot study. To study child/parent attitudes, a slightly modified version of the questionnaire questions was developed and assessed in a small pilot study. This probably served to increase the validity and reliability of our investigation. The high response rate in the questionnaire studies and few dropouts in the interview investigation also increase the validity and reliability.

Extent and causes of pain

We found highly significant differences as to how commonly pain occurs despite treatment, and how often more effective pain treatment could be possible. This probably reflects an overestimation and self-criticism on behalf of nurses and physicians. On the other hand, it might reflect an underestimation from children and parents due to denial and perhaps an overly optimistic belief that the medical profession does everything in its power to alleviate their pain and suffering.

Congruence between the groups was noted in their reports on causes of pain; a finding that confirms the results of previous investigations in children with malignancies (1-4,7).

Strategies to reduce procedural pain

The reports on strategies from children and parents concur with those from professionals and thus increase the validity of the instrument. When pain treatment failed, nurses and physicians estimated that a number of different psychological explanations were more important than did the families. One interpretation of this could be that professionals believe that psychological factors are of great importance for the experience of pain, whereas children and parents see inadequate pain relief merely as a failure of medication. The occurrence of pharmacological under-treatment and inadequate pain treatment resulting from unsatisfactory analysis of pain quality were not further investigated in this study.

Pain evaluation

About 75% of parents and 66% of professionals thought that parents are more capable of determining their child's pain than are professionals. This finding is not

consistent with that from a previous study where it is concluded that parent ratings may not provide a good indication of the amount of overt distress or the child's pain experience, and that nurse ratings of acute pain may most closely approximate objective assessment of pain and distress behavior (13). An explanation to this inconsistency could be that our questions did not discriminate between acute pain and longer term pain, and that our results may reflect views on the latter rather than on the former.

Parents and professionals agree that a child can produce reliable self-reports from as early as 4 years of age. This is in concordance with the fact that there are no reliable subjective scales for children under this age (18,19). Pain is by definition a subjective experience (20). The self-report technique is therefore the gold standard in pain assessment (19). However, a prerequisite for the use of this technique is an, at least, elementarily developed language, thus limiting the use in younger children.

Attitudes and information

Children and parents claimed that they never refused opioids for fear of addiction, but professionals reported some views to the contrary. Perhaps this reflects a change of attitudes due to education and information.

In conclusion, although the families and professionals in this study have many comparable views concerning pain in children with cancer, divergences also exist. To acquire a more accurate picture of the situation we must focus on the views of the children first, and then those of parents and professionals. In our study, nurses and physicians seeme

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