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Original Article

Procedural Pain in Lumbar Punctures and the Impact of Preparation in Pediatric Cancer Patients

Abstract

Aim: Childhood cancer patients are subjected to recurring painful medical procedures. In low- and middle-income countries (LMIC), where the majority of the world's childhood cancer patients live, pain management is often unsatisfactory due to limited resources. This study aimed to evaluate the possibility of conducting a preprocedural preparation for lumbar punctures (LPs) at a pediatric oncology unit in a LMIC and to assess whether this intervention would decrease procedural pain and fear. **Methods:** Patients aged 5–18 who underwent LPs between February 25, 2017, and April 12, 2017, were eligible and invited to participate. Included patients were interviewed to assess the procedural pain and fear in conjunction with the LP and the patients' understanding of why an LP was done. Closest caregivers and the medical staff were interviewed to compare the perceptions of pain. The study was conducted in two separate phases; patients included in the period of February 25–March 9 underwent LP according to routines without preparation while patients included in the period of March 10–April 12 received procedural preparation with information. Results from the interviews from the two study groups were compared. **Results:** Out of 79 patients who met the inclusion criteria, 76 were included and preparation was successfully implemented for 25 of them. The pain decreased significantly ($P = 0.022$) after preparation. The physicians underestimated the patients' pain ($P < 0.0001$). The understanding of the reason for the LP increased significantly among patients ($P = 0.0081$) and their caregivers ($P < 0.0001$). **Conclusions:** Preparation by preprocedural information, created to fit the situation at a state-run hospital in a LMIC, is feasible and efficient.

Keywords: *Low/middle-income countries, pediatric oncology, preprocedural preparation, procedural pain*

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Introduction

Globally, the incidence of childhood cancer is estimated to be around 165,000 new cases annually, of which 80% occur in low- and middle-income countries (LMIC).[1,2] All cancer patients experience pain at some point in the trajectory of their disease, which most often can be described as tumor-related pain due to the tumor's invasive growth or treatment-related pain due to procedures or to side effects to the given therapy. According to the International Association for the Study of Pain, pain is defined as "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life."[3]

Pain assessment in children

The various tools used for pain assessment in pediatric patients focus mainly on quantifying pain intensity and are roughly dividable into self-report tools and behavioral and physiological pain assessment tools. Due to the subjective nature of pain, self-report is considered to be the golden standard and should thus be used whenever it is possible. The most widely used self-report tools, validated for pediatric patients, are as follows: the Numeric Rating Scale (NRS), the Visual Analog Scale, the Faces Pain Scale (FPS), the FPS-Revised (FPS-R), the Wong-Baker Faces Pain Rating Scale (WBFPRS), and the Oucher Pain Scale. In general, pain levels over 3 on a 0–10 pain scale are considered to require a pain-relieving intervention.[4,5]

Like pain, fear is subjective and the golden standard in fear assessment is thus self-report. The Children's Fear Scale (CFS)

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is a self-report faces scale composed of five faces ranging from no fear (0) to maximal fear (4). CFS is validated for use in patients over 5 years of age.[6]

Procedural pain in childhood cancer patients

Procedural pain caused by blood sampling, lumbar puncture (LP), bone marrow (BM) aspirations, biopsies, and other procedures required for the diagnosis and treatment of cancer is a major part of the treatment-related pain in childhood cancer patients (the still-developing nervous system in a child, together with the psychological immaturity with fewer and less developed coping strategies, makes children especially sensitive to pain and to its consequences).[7] Procedural pain is influenced by expectations and earlier experiences of pain, as well as affective and emotional components, such as fear that is known to increase the perception of pain.[8-14]

There are different pharmacological as well as nonpharmacological methods to mitigate pain and fear during medical procedures.[12,13] Guidelines for procedural pain management in children recommend age-adequate information and preparation as the first intervention.[14,15] Together with topical anesthetics, preparation is regarded to be basic in pain management and recommended for all patients before procedures. Inappropriate management of procedural pain in children has been found to be associated with increased pain and anxiety in subsequent painful procedures[7,13,16-18] as well as increased pain sensitivity in adulthood.[7,10,19]

In pediatric oncology care in high-income countries, general anesthesia is the standard practice for providing sedation and analgesia during medical procedures such as BM aspirations and LPs. According to a survey of pediatric cancer hospitals in India, published in 2010, general anesthesia was not used anywhere in the country for BMs or LPs.[20,21] In 89% of the centers, some type of sedation or analgesia was used in LPs. In the majority of the surveyed centers, systemic sedation and analgesia using ketamine or midazolam were used, but at some centers, only local anesthetics were the standard of care. The authors describe lack of resources as a probable cause of this, as the use of systemic sedation and analgesia was considerably higher in private or cooperative hospitals compared to state-financed public hospitals.

Aim

The aim of this study was to evaluate the prevalence of and quantify the intensity of procedural pain and fear experienced by the pediatric cancer patients undergoing a LP and to assess the feasibility of a preprocedural preparation and its impact both on the comprehension of the procedure and on the level of pain. The secondary objective of this study was to compare the patients' self-reported pain with the pain assessments done by closest caregivers and by the medical staff performing the procedures.

Methods

This state-financed hospital is the only cancer hospital providing oncological treatment free of charge for patients below the poverty line in a catchment area of 85 million inhabitants in the states of Telangana and Andhra Pradesh. Medical, surgical, and radiation therapy is available, as is a specialized palliative care unit. There is a specialized pediatric oncology department with approximately 90 beds in two wards. The hospital has around 350 beds for in-house patients and a shelter for outpatients during treatment.

This study was a prospective interventional trial. First, a preparatory material for information about the LP procedure was put together specifically for this study, for this underprivileged group of patients in a low-resource hospital. This preparatory material included basic information on the anatomy of the spine, the spinal cord, and the spinal fluid and why and how a LP is performed. This material was presented to the patients and caregivers in Group B, during the second half of the study period. During the first study-period, LP: S were performed, according to routines at the hospital, without informational preparation, Group A. Data concerning levels of pain, fear, and understanding of the procedure were collected for comparison between the two groups of patients. Data on pain reports from the child, the caregiver, and the performing medical staff were also compared.

Inclusion and exclusion criteria

All patients between 5 and 18 years of age, admitted to the hospital and undergoing LP during the data collection period, were asked for participation in the study. Children unable of self-reporting and children, who for some reason were not interviewed on the same day as they had the procedure, were excluded. Patients who underwent LP multiple times during the study period were only included once.

Data collection

The data collection period extended from February 25, 2017, to April 12, 2017. Sociodemographic data such as age, sex, education, and occupation were obtained through interviews with the family. The diagnosis and date of the first admission to the tertiary cancer hospital were obtained from handwritten medical records. As data on the number of previous LPs were frequently incomplete in the patients' medical records, this information was asked for in the interviews with the family.

Patients were sequentially selected for the intervention with preprocedural preparation or not. Between February 25, and March 9, data were collected by interviewing patients who did not receive any information or preparation before the LP, henceforth referred as patients in Group A. The preparatory interventions and the data

collection from the patients who received preparation, Group B, started on March 10 and continued until April 12. However, some patients who went through a LP during this latter period missed out from the preprocedural preparation and were thus included in the nonintervention group, Group A.

Preprocedural preparation

For the purpose of this study, a film was recorded to serve as a preprocedural information for pediatric patients before their LP [Appendix 1]. The video was recorded in the local language Telugu and consisted of a 5-min long explanation about the anatomy of the spine, why the LP is performed and showing the procedure, on a teddy bear, and also demonstration a LP done in a pediatric patient at the hospital.

Questionnaire

Questions [Appendix 2] to map the procedural pain, fear during the procedure, knowledge of why the LP was done, and the cause for the LP (diagnosis) were phrased in an interview form. Patients, closest caregiver, and performing doctor were all asked for pain and fear levels; patients and caregivers were asked for knowledge of the LP and diagnosis for which a LP was done. The questionnaire was read out to all patients, caregivers, and doctors. It required 5–10 min to complete. The questions to the staff were asked in English immediately after each procedure. The questions to the patients and their caregivers were asked in the local language after returning to the ward from the procedure room. The goal was to interview each patient within 1 h from the procedure, and the time between procedure and interview was registered for each case.

Pain

The level of pain was assessed by a scale which was a combination of WBFPRS, NRS, and Colored Analog Scale, as this pain assessment tool was already in clinical routine at the pediatric ward at the hospital [Figure 1].

Fear

Fear during procedure was assessed with the CFS [Figure 2], and patients, caregivers, and doctors were all asked to grade the level of fear.

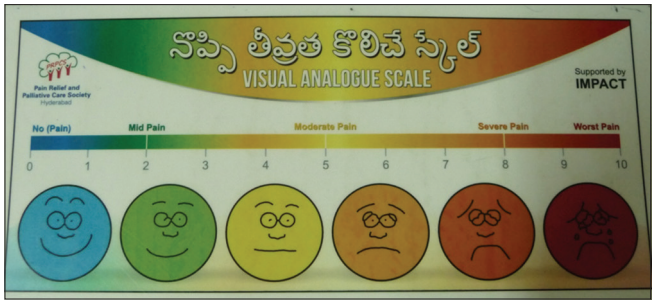

Figure 1: The pain scale used for procedural pain assessment

Reason for the procedure

In question number 3, the patient and the caregiver were asked whether they knew why the procedure was done. The obtained answers were classified as either "yes" or "no." Any answer stating that the purpose of the procedure was to treat or reduce the symptoms or the burden of the disease was classified as a "yes."

Diagnosis

In question number 4, the patient and the caregiver were asked whether they were familiar with which disease the patient suffered from. Any answer stating that the disease was a form of cancer was classified as a "yes."

Ethical approval

Ethical approval for the study was granted by the ethical committee at hospital. Participation in the study was voluntary. Oral and written information about the study was supplied to all the patients and their caregivers, and written consent for participation was obtained from each caregiver by collecting a signature or a thumb imprint, if illiterate. The participants could at any point withdraw from the study without any consequences.

Statistical analysis

Before the data collection, a statistical power calculation was carried out. We assumed the true mean difference in NRS score between children having intervention and children not having intervention to be 3 units and the pooled standard deviation to be 6. Using these assumptions, a total number of 128 patients were needed to be able to reject the null hypothesis that the group means are equal with 80% power. Probability of Type I error (alpha) associated with this test was 5%. The true mean difference in NRS score between children and parents, as well as between children and doctors, was assumed to be 2.5 units, the standard deviation to be 6, and the correlation between the groups to be 0.4. Using these assumptions, a total number of 57 pairs (patient and parent, patient and doctor) were needed to be able to reject the null hypothesis that the true mean difference is 0 with 80% power. Probability of Type I error (alpha) associated with this test was 5%.

The statistical calculations were carried out in Excel 2010 and in SAS Enterprise Guide, version 6.1. As the obtained data were not symmetrically distributed and the study groups were relatively small, the median was used as the measure of central tendency. As the NRS is an

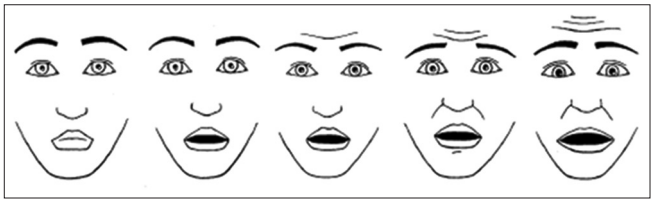

Figure 2: Children's Fear Scale used for fear assessment

ordinal scale that consists of a limited number of values, the Mann–Whitney U-test was used to investigate if there were differences between Group A and Group B. For the binomial data (knowledge of diagnosis and understanding of the reason for the procedure), Fisher's exact test was used to investigate if there were differences between the two study groups. Since the comparison between children and caregivers, as well as children and health-care personnel, consisted of paired samples, Wilcoxon signed-rank test was used to investigate if there were differences between the pain scores within the pairs. $P = 0.05$ was considered statistically significant.

Results

In total, 79 patients met the inclusion criteria for this study and were asked for participation. Caregivers to all patients gave their consent to participate. Three patients were later excluded because they were not interviewed on the day of the procedure or were unable of providing a self-report [Figure 3]. Group A consists of 51 patients who underwent LP without preparation and Group B consists of 25 patients who underwent the preparatory intervention before the LP. The study was limited by time constraints, and we did not reach the planned inclusion of 128 children.

Baseline data

Sociodemographic data such as age, gender, religion, educational level, family income, caregiver's educational level, and caregiver's occupation were similar between the two study groups [Table 1]. The distribution of diagnoses within the two groups, see Table 1.

The ages of the patients ranged between 5 and 18 years with a median of 10 (5–18) years in Group A and 9 (5–16) years in Group B. The majority of the patients attended school and lived in nuclear families in a rural setting. The attending caregiver was the mother in 67% of the cases, almost half of the caregivers were illiterate, and most caregivers had occupations within daily labor. The majority of the patients had been diagnosed with acute lymphoblastic leukemia and the second most common diagnosis was acute myeloid leukemia. The few remaining patients had the diagnoses of Burkitt's lymphoma, anaplastic large cell lymphoma, and Ewing sarcoma. Out of the 79 patients, only 14 patients underwent the LP for the first time, and the median number of previous LP in the remaining 64 patients was 4 (0–40). For one patient, data were not found regarding previous LP, and for two patients, the number of previous LP was not known.

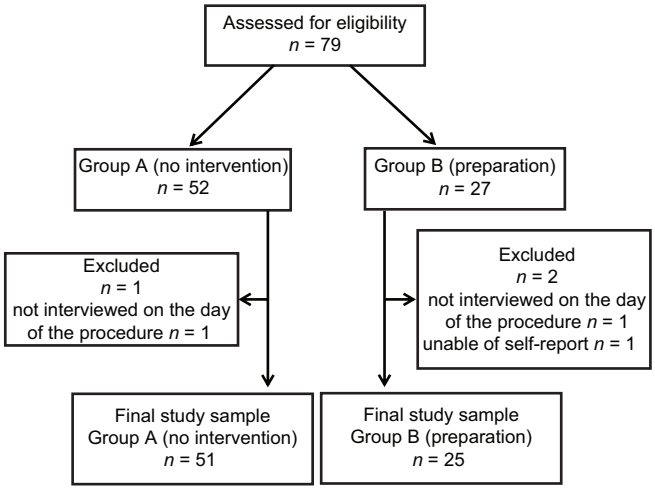

Figure 3: Flowchart of participants

Interviews

The majority of the interviews were conducted by the same interpreter. However, in total, four different interpreters were involved in the data collection. Two patients and their caregivers did not speak the local language but spoke English and were therefore interviewed in English by the author. In Group A, the median time between procedure and interview was 40 (5–225) min. In Group B, the median time between procedure and interview was 25 (5–190) min.

Preprocedural preparation

In Group B, the informational video was shown to the children together with their caregivers on the day of the procedure, about 1 h before the procedure. A nurse or a social worker gathered the patients and their caregivers as a group, from 1 to 11 patients with caregivers on each occasion, in a separate room and showed the video on a laptop. Afterward, there was time for questions and discussion. The total duration of the preparation was around 15 min and most often four to five patients with caregivers participated.

Topical anesthesia

Before the LP, topical anesthesia (lidocaine and prilocaine cream) was applied to most, but not to all patients included in this study. In Group A, 8/51 (16%) and, in Group B, 1/25 (4%) of the patients did not receive topical anesthesia. The time of application was not registered but is estimated to be 5–45 min before the procedure.

Pain

The median pain score of the patients was 4.0 (0–10) in Group A and 3.0 (0–8) in Group B, with a significant difference between the groups ($P = 0.022$). The median pain score estimated by the caregivers was 4.0 (0–10) in Group A and 2.0 (0–10) in Group B, with a significant difference between the groups ($P = 0.0090$). The median pain score estimated by the doctors performing the LPs was 2.0 (0–6) in Group A and 2.0 (0–7) in Group B, with no significant difference between the groups ($P = 0.6875$) [Table 2 and Figure 4].

The median difference between each child's self-reported pain score and its caregiver's estimated pain score (i.e., the caregiver's score minus the child's score) was 0.0 ((-5)4), with no difference between the pain scores ($P = 0.9828$). The median difference between each child's

Table 1: Sociodemographic and other baseline data in the two study groups

	Group A (no intervention)	Group B (preparation)
Sample size	51	25
Sex	Female=19 (37%), male=32 (63%)	Female=11 (44%), male=14 (56%)
Age, median (minimum-maximum) years	10 (5-18)	9 (5-16)
Diagnosis (%)		
ALL	48 (94)	18 (72)
AML (included APML)	1 (2)	5 (20)
Other	2 (4)	2 (8)
Age adequate education	48 (94)	25 (100)
Religion		
Christian	7 (14%)	2 (8%)
Hindu	34 (67%)	18 (72%)
Muslim	10 (20%)	5 (20%)
Urban or rural	U=17 (33%) R=34 (67%)	U=7 (28%) R=18 (72%)
Relation of primary caregiver		
Mother	39 (76)	12 (48)
Father	9 (18)	12 (48)
Other	3 (6)	1 (4)
Caregiver education		
No education	23 (45)	10 (40)
1-10 years of school	11 (22)	7 (28)
10-12 years of school	14 (27)	5 (20)
Higher education	3 (6)	3 (12)
Caregiver occupation		
Agriculture	7 (14)	4 (16)
Daily labor	24 (47)	13 (52)
Housewife	14 (27)	4 (16)
Other	6 (12)	4 (16)
Mean monthly family income (%)		
<5000 INR (≈77 USD)	13 (25)	8 (32)
5000-10 000 INR (≈77-155 USD)	36 (71)	16 (64)
>10,000 INR (≈155 USD)	2 (4)	1 (4)
Family type (nuclear or joint)	N=44 (86) J=7 (14)	N=19 (76) J=6 (24)

ALL – Acute lymphoblastic; AML – Acute myeloid leukemia; APML – Acute promyelocytic leukemia; INR – Indian Rupee; USD – United States Dollar

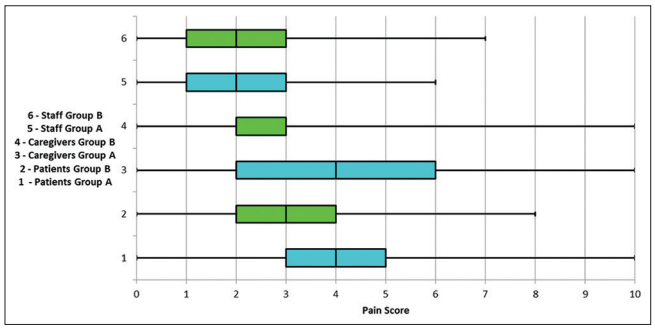

Figure 4: Pain scores for procedural pain experienced during a lumbar puncture, reported by patients, caregivers, and staff in Group A (no intervention) and Group B (preparation)

self-reported pain score and the pain score estimated by the doctor who performed the LP on that child (i.e., the doctor's score minus the child's score) was 2.0 ((-4)7), with a significant difference between the pain scores ($P < 0.0001$), evidently an underestimation of the child's pain [Table 3].

Fear

The median fear score of the patients was 2.0 (0–4) in Group A and 1.0 (0–4) in Group B, with no significant difference between the groups ($P = 0.7681$). The median fear score estimated by the caregivers was 2.0 (0–4) in Group A and 1.5 (0–4) in Group B, with no significant difference between the groups ($P = 0.7597$). The median fear score estimated by the doctors performing the LPs was 1.0 (0–4) in Group A and 1.0 (0–4) in Group B, with no difference between the groups ($P > 0.8228$) [Table 2]. Furthermore, comparisons of fear scores reported by the patients, their caregivers, and the doctors showed no significant differences between the self-report and the estimations [Table 3].

Reason for the procedure

In Group A, 7/51 (14%) of the patients knew why the procedure was done, as compared to 11/25 (44%) of the patients in Group B, with a significant difference between the groups ($P = 0.0081$). In Group A, 19/51 (37%) of the

Table 2: Comparison of pain scores and fear scores reported by patients, caregivers, and staff in the two study groups

Variable	Responder	Group A (no intervention)	Group B (preparation)
Pain score (0-10)	Patient		
	n (missing)	51 (0)	25 (0)
	Mean (SD)	4.3 (2.2)	3.3 (1.9)
	Median (IQR)	4.0 (2.0)	3.0 (2.0)
	Q1; Q3	3; 5	2; 4
	Minimum; maximum	0; 10	0; 8
	P[a]		0.0217
	Caregiver		
	n (missing)	46 (5)	24 (1)
	Mean (SD)	4.4 (2.4)	3.0 (2.0)
	Median (IQR)	4.0 (4.0)	2.0 (1.0)
	Q1; Q3	2; 6	2; 3
	Minimum; maximum	0; 10	0; 10
	P[a]		0.0090
	Staff		
	n (missing)	51 (0)	25 (0)
	Mean (SD)	2.2 (1.7)	2.4 (1.8)
	Median (IQR)	2.0 (2.0)	2.0 (2.0)
	Q1; Q3	1; 3	1; 3
	Minimum; maximum	0; 6	0; 7
	P[a]		0.6875
Fear score (0-4)	Patient		
	n (missing)	51 (0)	25 (0)
	Mean (SD)	1.8 (1.1)	1.7 (1.0)
	Median (IQR)	2.0 (1.0)	1.0 (1.0)
	Q1; Q3	1; 2	1; 2
	Minimum; maximum	0; 4	0; 4
	P[a]		0.7681
	Caregiver		
	n (missing)	46 (5)	24 (1)
	Mean (SD)	1.8 (1.1)	1.8 (1.0)
	Median (IQR)	2.0 (1.0)	1.5 (1.0)
	Q1; Q3	1; 2	1; 2
	Minimum; maximum	0; 4	1; 4
	P[a]		0.7597
	Staff		
	n (missing)	49 (2)	25 (0)
	Mean (SD)	1.7 (1.3)	1.8 (1.3)
	Median (IQR)	1.0 (2.0)	1.0 (2.0)
	Q1; Q3	1; 3	1; 3
	Minimum; maximum	0; 4	0; 4
	P[a]		0.8228

[a]Mann-Whitney U-test. SD – Standard deviation; IQR – Interquartile range (Q3-Q1)

caregivers knew why the procedure was done, as compared to 22/25 (88%) of the caregivers in Group B, with a significant difference between the groups ($P < 0.0001$) [Figure 5].

Diagnosis

In Group A, 14/51 (27%) of the patients knew that they had cancer, as compared to 10/25 (40%) of the patients in Group B, with no significant difference between the groups ($P > 0.3$). In Group A, 48/51 (94%) of the caregivers knew that the patient had cancer, as compared to 25/25 (100%) of the caregivers in Group B, with no significant difference between the groups ($P > 0.3$) [Figure 6].

Table 3: Differences between paired pain and fear scores reported after the lumbar punctures. The difference is given by each observer's pain score minus each respective patient's pain score

Variable	Patient versus caregiver	Patient versus staff
Pain score (0-10)		
n (missing)	70 (6)	76 (0)
Mean (SD)	0.0 (2.0)	1.7 (2.3)
Median (IQR)	0.0 (3.0)	2.0 (3.0)
Q1; Q3	−2; 1	0; 3
Minimum; maximum	−5; 4	−4; 7
P[a]	0.9828	<0.0001
Fear score (0-4)		
n (missing)	70 (6)	74 (2)
Mean (SD)	0.0 (0.9)	0.0 (1.5)
Median (IQR)	0.0 (1.0)	0.0 (2.0)
Q1; Q3	−1; 0	−1; 1
Minimum; maximum	−3; 4	−3; 4
P[a]	0.6744	0.9069

[a]Wilcoxon signed-rank test. SD – Standard deviation; IQR – Interquartile range (Q3-Q1)

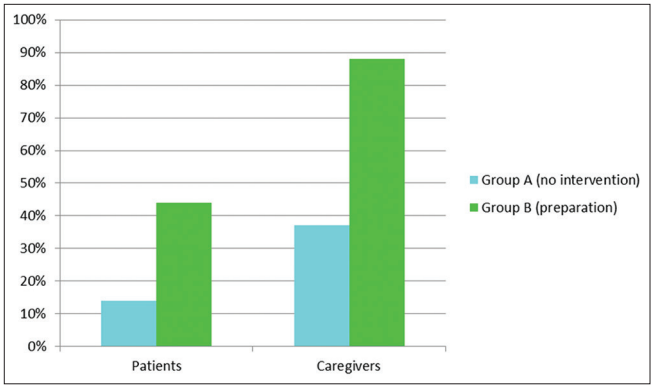

Figure 5: Understanding of the procedure among the study participants in Group A (no intervention) and Group B (preparation). Percentage of patients and caregivers who knew why the lumbar puncture was done

Discussion

In the present study, we have shown that it is possible to develop comprehensible information material for preprocedural preparation in a low-resource setting and the feasibility to perform group preparation before a painful medical procedure with families with poor socioeconomic background and low educational level in a LMIC. We found that this preparation led to significantly lower self-reported pain ratings among pediatric cancer patients undergoing a LP ($P = 0.022$).

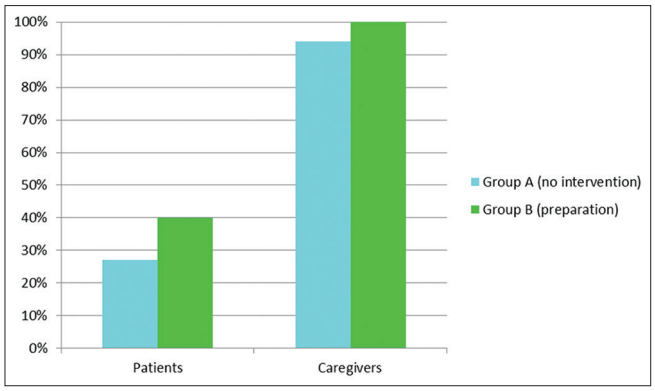

Figure 6: Knowledge of diagnosis among the study participants in Group A (no intervention) and Group B (preparation). Percentage of patients and caregivers who knew that the patient had cancer

Furthermore, we found that the understanding of why the procedure was done increased significantly among both the patients and their caregivers following this preparatory intervention. The preparation contained no information about cancer, and there was no significant difference in knowledge of the diagnosis among the patients and the caregivers in the two study groups. This further supports our conclusion that the difference in understanding the reason for the LP procedure was a consequence of the preparatory intervention and not of prerequisite differences in the level of knowledge between the two study groups.

Our finding that doctors who performed the LPs underestimated the procedural pain experienced by their patients ($P < 0.0001$), which is in line with the findings of many other researchers depicting that i.e medical personnel's underestimation of children's pain, and that is a common reason for the under-treatment of pain in pediatric patients.[12,15]

There are multiple other studies that suggest that preparation before medical procedures or surgery can help to reduce anxiety in pediatric patients and their parents and increase their understanding of the procedure.[22-26] However, the results of these studies are often not statistically significant. Moreover, many of these publications study combinations of different nonpharmacological interventions, making it difficult to draw conclusions specifically about preprocedural information. Two review articles that aim to summarize the current state of knowledge about preprocedural preparation in childhood patients describe that the quality of evidence for preparatory information is low, but that the recommendation for such interventions is nevertheless strong.[12,13] In the present study, with 76 children included, the results are significant and we postulate that the significance would increase had we included more patients.

There are several sources of potential bias to this result, which need to be discussed. In our study sample, variations in the use of topical anesthesia were observed, as well as variations in the number of previous LP procedures that each patient had already experienced. Both of these factors can be assumed to influence a patient's experience of pain and fear from the procedure included in our analysis. On the other hand, the administration of the only analgesic, i.e. the topical formula, was not provided in a timely correct manner, as the anesthetic effect is evident first after around 1 h, and the time between application and the procedure in this study was estimated to be 5-45 min.

We chose to conduct the interviews with the pain scale that was in use at the hospital and familiar to both the staff and many of the patients, a WBFPRS with some additional features, despite the limitations associated with the use of a nonvalidated combination of multiple pain scales, as well as the emotional appearances of the faces in the WBFPRS. Pain assessment in children is a challenge in clinical practice. In the youngest children, obtaining a pain report is difficult and can be dependent on the interviewer's approach to the child, as well as the environment, mood, and character of the child. Despite extensive research, one single pain assessment tool suitable for all children has not been found. According to the systematic review by Tomlinson *et al*., the WBFPRS is preferred by both children and parents.[5] However, the smiles and tears of the WBFPRS might confound pain intensity with affect when obtaining a report about a medical procedure. Some studies suggest that the use of WBFPRS generates higher pain scores than the use of other validated pain faces scales, such as the FPS-R.[5,6]

In the present study, we produced a video showing in simple ways what an LP is, why it is done and explaining the anatomy and structures of the back and the spinal cord. One could argue that ideally, preprocedural preparation should be individualized. Younger children should be informed and prepared by playing, adolescents should be given the time and possibility to process and discuss the given information without the caregivers' presence, and the amount of information should differ for each patient according to their individual needs, which is in line with what many authors avocates.[14,15] Preparation in a group, as in the present study, is associated with limitations and cannot be expected to give the same positive effects that individual preparation. Further, we believe that the preprocedural preparation would be better if given verbally by a nurse or a social worker with adequate training and engagement, rather than as a video. However, given the limitations in a busy and crowded department in an underresourced hospital, the positive results of our study are encouraging. An existing informational material, as the video produced here, is a robust method, and the quality of information will thus not depend on the presence and availability of trained staff. Furthermore, in a low-resource setting, preparation in group is less vulnerable and less demanding and thus an acceptable alternative to individual counseling.

Conducting this study was associated with several ethical considerations. Administering our questionnaire after

the procedures might have caused negative emotions, as sensitive questions regarding the family situation and the reason for the child's hospitalization were asked. In the setting where this study was performed, such questions are rarely freely discussed. To raise questions about the disease and situation of every individual patient could have a negative impact on the emotional and psychological well-being of the child and its parents. This is problematic, as resources at this and similar low resource hospital are scarce and the possibilities for individual counseling are limited. However, as the interviews were conducted by interpreters from the local cultural background, much caution and attentiveness were used when asking sensitive questions. Overall, the potential positive effects of creating new routines for patient information and preprocedural preparation, as well as of raising the awareness among the staff at the pediatric oncology unit, are believed to overweigh the risk of possible negative effects.

This study was conducted in an undermanned, underresourced hospital, which is associated with many limitations, including unpredictable turns of the day and logistical obstacles. First, we did not reach our level of inclusion, 76 children were included instead of the planned 128. Second, the questionnaire used for this study was written in English and translated by the interviewer while conducting the interviews in Telugu. The interviews were conducted in the ward, sometimes in a crowded environment. Thus, there is a reason to doubt the total homogeneity of the interviews. However, all but a few interviews were conducted by the same interpreter, which decreases the risk of bias due to different formulation of questions. It should also be noted that regardless of the available resources, interviewing young children in a completely homogeneous way is not possible, as some children require more explanation and introduction than other in order to answer questions. Further, the interviews with the patients and caregivers were mostly conducted in the presence of both the patient and the caregiver, allowing them to be biased by each other's answers. Furthermore, other patients and caregivers were present during some interviews, which could have influenced the answers of the interviewees.

A strength of this study is that nearly all the eligible patients participated, meaning that almost all patients who underwent a LP during the data collection period were interviewed. This allows us to assume that the results can be generalized to similar health-care settings in LMIC with lacking resources and a high patient burden from underprivileged families, a situation for the majority of childhood cancer patients in the world. In our study, the preparation had a positive effect, despite its many weaknesses. Hence, we conclude that, even in settings where time and resources do not allow ideal preparation, information and attention around an upcoming medical procedure give the patients and their families a better understanding and a more positive experience. It is of importance for hospitals such as where the study was undertaken to acknowledge that efficient preparation can be achieved with small means and that there is a need of increased awareness, as well as better pain relief, when performing medical procedures in children.

Conclusions

The majority of pediatric patients who undergo LPs at the hospital where this study was conducted experience treatment-requiring levels of procedural pain. Medical doctors who perform the LPs underestimate the patients' pain. Preprocedural information and preparation, adapted to the situation at the hospital, are feasible and are found to be efficient in informing patients and their caregivers about the reason for the LP. In the present study, we found a decrease in self-reported procedural pain following preprocedural preparation. However, in addition to information, further pain-relieving interventions are required to achieve a satisfactory procedural pain management in childhood cancer patients undergoing LP in low-resource settings.

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Conflicts of interest

There are no conflicts of interest.

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Appendices

Appendix 1: Questionnaire

Questions to be asked to the patients:

1. How much pain did you experience during this procedure? Please point on this scale that indicates no pain here (point on face 0 and on 0 on Colored Analog Scale [CAS]) and the worst pain you can imagine here (point on face 10 and on 10 on CAS).

If needed: This face does not hurt at all (0), this face hurts just a little bit (2), this face hurts a little bit more (4), this face hurts even more (6), this face hurts a whole lot (8) and this face hurts worst (10). Which face did you feel like during the procedure?

2. These faces are showing different amounts of being scared. This face (point on face 0) is not scared at all, this face is a little bit more scared (point on face 1), more scared (point on face 2), even more scared (point on face 3) and the most scared possible (point on face 4). Have a look at these faces and choose the one that shows how scared you were during the procedure.
3. Do you know why this procedure was done?
4. Do you know which disease you have?

Questions to be asked to the care-givers:

1. How much pain do you think that your child experienced during this procedure? Please point on this scale that indicates no pain here (point on face 0 and on 0 on CAS) and the worst pain you can imagine here (point on face 10 and on 10 on CAS).
2. How much fear do you think that your child experienced in connection with this procedure? Please point on this scale that indicates no fear here (point on face 0) and the worst fear you can imagine here (point on face 4).
3. Do you know why this procedure was done?
4. Do you know which disease your child has?

Questions to be asked to the staff performing the procedure:

1. How much pain do you think that the patient experienced during this procedure? Please point on this scale that indicates no pain here (point on face 0 and on 0 on CAS) and the worst pain you can imagine here (point on face 10 and on 10 on CAS)
2. How much fear do you think that the patient experienced in connection with this procedure? Please point on this scale that indicates no fear here (point on face 0) and the worst fear you can imagine here (point on face 4).

Appendix 2: Script for preprocedural preparation

Children, soon you will have a procedure called intrathecal chemotherapy. For this, you will go to a different part of the hospital, where you might not have been before. There is usually a big crowd of people there and a lot of noise. Then there is a special room for the intrathecal therapy. In the room, there will be quite many people that you have not seen before. A doctor, a nurse, and a few other adults. But you will go there together with your parents. When it is your turn, you will be asked to lie down on a bed in this position (show). So you will try to look like a ball, showing your back to the doctor. Try it! Then, the parents, you will hold your child like this (show all the parents).

Then if you touch the middle of your back with your hand, you can feel something hard, this is called the spine. Do you feel it? Try! Inside the spine there is a fluid, it looks like water. This water is inside all your spine, all the way up to your head and also around your brain. Sometimes, when you are sick, the disease can swim around in this water. What we need to do now, is to put a medicine into the water, which will try to catch the disease and take it away. The medicine will also swim around all your back and around your brain, trying to catch the disease and take it away. If the disease goes away, you feel much better and you are not sick any more. This is why it is important to do this procedure.

In order to put the medicine inside the water in your back, we need to put a needle into the place in your back, where this water is. So when you lie on the bed like this, the doctor will touch your back, to find the place where the water is. Then, s/he will wash your back with something wet and then to put the medicine inside, s/he will put a small needle in the place where the water is. This can hurt a bit, but it is very quickly over. About half an hour before the procedure, you will get a cream on your back – this cream makes the pain from the needle smaller.

When we are finished, we put a little plaster on your back and then you have to lie down for half an hour. After that you can go to play or do whatever you want again. It is not dangerous to put the needle in your back. It hurts a bit, but then it's over.

So when we do the procedure, you have to lie in this position – like you are trying to be a ball. You have to lie very still and because of this, your parents will hold you very hard, so that you can't move. It is scary when somebody is holding you so hard, but it is necessary to make sure you don't move and we can make a good procedure. Try to breathe calmly and stay still and think of something else, not the procedure, for example, you can tell your mum or dad about your favorite place or favorite game or something else that you like.

For the parents, it is important to stay calm, because then also your child is calm. It is good if you distract your child, maybe by telling them a story or playing a spoken game with them. If your child is very small, it is also important that you hold the child firmly, so firmly that they cannot at all move – this will make your child upset but it will make the procedure much quicker and less scary if you do it. You can bring a cushion/teddy bear for your child to hug if you think it makes it easier for them to lie still in the ball position. Does anybody have any questions?