

Original Research Article

Parental experiences of procedural pain in children during hospitalization at a tertiary hospital, Kaski district: a qualitative study

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ABSTRACT

Background: Pain experiences are very common during childhood as they are frequently exposed to minor medical interventions such as venipuncture, immunization and common accidental injuries in their everyday life. The objectives of the study were to explore the lived-in experiences of parents of procedural pain in children during hospitalization and describe the various dimensions of the lived-in experiences of parents towards painful procedures in children during hospitalization.

Methods: This was a qualitative descriptive phenomenological study conducted among 15 dyads receiving treatment in the pediatric unit of Gandaki Medical College and Teaching Hospital, Nepal recruited through purposive sampling technique from 15th June to 14th July 2023. Data was collected using a semi-structured interview guide through one-to-one in-depth interviews. Colaizzi's approach was adopted to analyze the data. Themes and sub-themes were generated and the findings were presented.

Results: Parental lived-in experiences included experiences related to their child's pain, means of distraction, the role of the healthcare provider, and effective pain management skills by self. Emotional experiences of the parents and child during the invasive procedure were frequently recorded which reflected their anxiety, fear, and nervousness to the extreme level. Parents also expressed a lack of knowledge regarding the management of pain during the procedure which could have been facilitated by the healthcare professionals.

Conclusions: Parents had to deal with anxiety and nervousness arising during invasive procedures carried out as a part of their child's treatment. There is a need for an adequate explanation of the procedure by healthcare professionals to minimize the physical and psychological discomfort experienced by the dyads.

Keywords: Parents, Children, Anxiety, Lived-in, Experience, Procedural pain

INTRODUCTION

Pain experiences are very common during childhood as they are frequently exposed to minor medical interventions such as immunization, and common accidental injuries in their everyday life.^{1,2} Most children learn to react toward pain by observing their parent's/caregiver's response towards facing pain.³ Various national and international organizations including WHO have more emphasis on the importance

of pain management for children during hospitalization.⁴ Hospital and ambulatory services often encounters procedures involving pain, with up to 80% of hospitalized children having at least one painful procedure every 24 hours.⁵ Venipuncture and intravenous (IV) insertions are the most common painful procedures in the pediatric ward.⁶

Whether a child is admitted to the hospital for treatment of a painful disease condition or experiences common

procedural-related pain while admitted in the hospital, it is very predictable that their pain will be ignored and undertreated.⁷ Caregivers may also experience anxiety and distress during their child's painful procedures.⁸ A study of caregivers witnessing their child receiving intravenous cannulization procedure demonstrated a statistically significant increase in parent's own heart rate and anxiety which dramatically relieves about half of their child's stress during the recovery process from pain.⁹ Various evidence-based research regarding the effect of pharmacological medications such as topical anesthetics and nonpharmacological psychological interventions such as hypnosis, distraction, and imaginary therapy have positive effects in managing pain and physical distress in children undergoing any painful procedures.^{6,10}

Results of many research have shown that inadequate pain treatment can have devastating effects on the child's life by resulting in extended length of hospitalization, slower healing from pain and wound, altered pain processing, depression, anxiety, and substantial social and economic costs to their family and society.⁴

During hospitalization painful procedures are unavoidable to treat the child. Some simple strategies such as providing a comfortable position, breastfeeding the young child, pacifier sucking for an older child, using less painful approaches, advocating distraction strategies such as reading a story, showing an animated video, playing interactive games, blowing bubbles, showing love and affection by the parents can ease the child during painful procedures.¹¹

Most of the children show active participation in pain management and the caregiver has expectations from the health professionals that they will reassure the child and parents about the procedure being performed is safe and painless. Parents wish to reduce the child's anxiety and pain during common needle-related medical procedures, during the procedure parents also express anxiety and show concern towards self -being present during the procedure. Parents seek adequate support and prior information about the medical procedures to lessen the intensity of the felt pain of parents towards the procedural pain of their children.¹²

To manage pain in children, a child-friendly environment in the ward such as making colorful wall décor, cartoons, animations, and pictures in the ceiling, providing children with developmentally appropriate toys, and playing hide and seek games can also distract children during the procedure. Some children are also well supported for pain management through deep breathing exercises, hypnosis therapy, music therapy, and expressing love through using soothing lovable words.¹¹

A study done in Finland about parents' perceptions of their child's pain assessment in hospital care reveals that children experienced moderate (36%) to severe pain

(42%) during hospitalization. The intensity of pain was more during the needle-related procedures. 83% parents also expressed that parental views on their child's pain might play a vital role.¹³

Inadequate pain management in early and middle childhood leads to problems regarding fear of medical events, avoidance or overuse of medical care, and heightened sensitivity to subsequent medical care.¹⁴ Children are at high risk for pain under-treatment in the hospital setting.^{15,16}

Caregivers are also not approachable for taking care of their children all the time during hospitalization and they may not understand healthcare workers instructions. Parenting may be difficult to maintain when a child is hospitalized. Parents' feelings about this experience can be a source of information for improving the way caregivers take care of and support the child.¹⁷

When a child's pain is undertreated, more than 60% of children and up to 50% of youth develop needle fears which can then extend till their adulthood.¹⁸ These experiences can lead to more tailored information for parents, better communication with parents, and more parental involvement in the care that is personalized to each child and parent. The main objective of this phenomenological study was to collect the lived-in experiences of parents about procedural pain in children during hospitalization.

METHODS

Study design

We used a qualitative Colaizzi's descriptive phenomenological research approach to document the lived-in experience of parents related to procedural pain in children during hospitalization. The strength of this type of research was that it provided a thorough exploration of what the parents were thinking and feeling exactly about a certain topic, question, or situation. This study was conducted in a tertiary-level teaching hospital named Gandaki Medical College Teaching Hospital and Research Center, Kaski District, Nepal from 15th June to 14th July 2023. The parent-child dyads who were admitted and receiving treatment in the pediatric medical and surgical unit in the last 48 hours with a history of any painful procedure during the period of treatment were recruited in this study.

Sampling and sample size

We adopted the non-probability purposive sampling technique for the study to gain an in-depth understanding of parents' experience with child's pain. All participants meeting the criteria were approached by the researcher herself, researcher reconfirmed the patient child age group to be from 3 to 6 years and invited their parent to participate in the study after obtaining informed written

consent. Based on literature the sample size was assumed to be 15-20. Parents of the child undergone any painful procedure within the last 4-6 hours, willing to participate in the study, and who can understand and respond in Nepali were included in the study whereas parents of child with a serious illness and requiring oxygen or mechanical support were excluded from the study. Researcher terminated the data collection process after 15 samples as saturation of the information obtained was felt.

Data collection

Data collection was done from 15th June to 14th July 2023, through in-depth interviews using a semi-structured interview guide prepared by the researcher herself with an extensive review of the literature. Every single interview was conducted on-one-to basis. Researcher arranged a private space for conducting the interview and parents were also given a choice whether to get interviewed along with their child or without their child. Most of the parents choose to be interviewed along with the child's presence. The interview took 35-40 minutes and only one interview was conducted per day. The semi-structured interview guide consisted of two sections: section I: Questions related to demographic information of dyads; section II: Questions related to parental experiences about procedural pain in their children.

All the interviews were audio recorded, listened to carefully, and transcribed into verbatim afterward by the research team. Initial code was developed and then themes and sub-themes were generated and analyzed through Colaizzi's approach. The code prepared manually was logically categorized and processed along with the themes and subthemes to match the study objectives.

Ethical consideration

Ethical approval was obtained on 13th June 2023 from Institutional Review Committee of Gandaki Medical College Teaching Hospital and Research Center (Ref no: 291/079/080). Administrative approval to conduct the study was obtained from medical superintendent and Head of Pediatric department of GMCTHRC. Informed written consent was obtained from each parent. They were informed that the entire conversation will be recorded and used for present research purpose only. Confidentiality of the information was guaranteed. Privacy was maintained by taking the interview in the procedural room either in the presence or absence of their child upon their choice.

RESULTS

Among the 15 participants, 6 participants chose to be interviewed along with their child and 9 participants were interviewed without their child's presence. Socio-demographic characteristics of the parents and children are presented in Table 1 and Table 2 respectively.

Thematic analysis of the interview is framed in themes and after in-depth analysis, the themes are again categorized into sub-themes and are presented in Table 3, further description of subthemes with the example statement of parents is discussed below.

Table 1 reveals the socio demographic characteristics of parents. Majority 13 (86.7%) of participants belonged to the age group 20-40 years, regarding gender 12 (80%) were female participants among them 12 (80%) were mothers, regarding ethnicity, more than half 8 (53.3%) belonged to Dalit, regarding religion almost all 14 (93.3%) were following Hinduism, regarding participants educational status, more than half 10 (66.7%) had completed their secondary level education, regarding the occupation of participants nearly more than one third 6 (40%) were homemaker.

Table 1: Demographic variables of parents.

Demographics	N (%)
Age (in years)	
20-40	13 (86.7)
40-60	1 (6.7)
60-80	1 (6.7)
Gender	
Male	3 (20)
Female	12 (80)
Relation with child	
Father	3 (20)
Mother	12 (80)
Ethnicity	
Dalit	8 (53.3)
Relatively advantaged janajati	1 (6.7)
Upper caste group	6 (40)
Religion	
Hinduism	14 (93.3)
Buddhism	1 (6.7)
Educational level	
Primary level	3 (20)
Secondary level	10 (66.7)
Bachelor level	2 (13.3)
Occupational status	
Homemaker	6 (40)
Business	4 (26.7)
Agriculture	4 (26.7)
Foreign	1 (6.7)

Table 2 reveals the socio-demographic characteristics of children, nearly half of the population 7 (46.7%) belonged to 6 years age group, more than half 10 (66.7%) of children were male, more than half 9 (60%) of children were studying in primary level, almost all 14 (93.3%) of child were diagnosed with acute illness, one third 4 (26.7%) of child had recently visited hospital in between 1-5 months, regarding hospital admission more than half 10 (66.7%) were admitted in hospital once previously,

regarding number of intravenous insertion/blood withdrawal procedure during hospitalization all 15 (100%) participants had insertions between 1-5 times.

Table 2: Demographic variables of child (n=15).

Demographics	N (%)
Age (in years)	
3	2 (13.3)
4	5 (33.3)
5	1 (6.7)
6	7 (46.7)
Sex	
Male	10 (66.7)
Female	5 (33.3)
Grade in school	
Kindergarten	6 (40)
Primary level	9 (60)
Health status of child	
Acute illness	14 (93.3)
Chronic illness	1 (6.7)
Previous hospital visit (months)	
No visit	4 (26.7)
1-5	4 (26.7)
6-10	2 (13.3)
11-15	3 (20)
>16	2 (13.3)
Admission to hospital	
1	10 (66.7)
>1	5 (33.3)
No of intravenous insertion/blood withdrawal during hospitalization	
1-5	15 (100)

Theme 1: Experience related to their child's pain

This theme covers the emotional experience of the caregiver during the cannulization procedure in a child, the duration of pain, and emotional experience of a child towards the procedure.

Most of the participants were anxious and scared before and during their child's cannulization procedure, caregivers expressed that they were very panicky before the procedure.

"I felt anxious and scared but after some time I got adjusted to the situation. I felt like crying aloud." (P1, mother, 5 years old).

"My baby's veins get dilated when pricked, and he is very scared of needles. I wished that the staff sister would do the vein opening without creating much pain for my child. I felt like my hands were paining when my child was undergoing IV insertion." (P3, mother, 3 years old). Some of the participants also showed satisfaction with the healthcare provider's effective role in reducing their pain perception during the procedure.

Table 3: Themes and sub themes of parent's lived-in experience of procedural pain in children during hospitalization.

Themes	Subthemes
Experience related to their child's pain	Emotional experience of caregiver during cannulization procedure in child
	Duration of pain
	Emotional Experience of child toward the procedure
Experience related to means of distractions	Toys used during a painful procedure
	Coping mechanism of child
	Communication and counselling by parents
Experience related to role of healthcare provider	Explanation of procedure
	Parental expectations towards the procedure
	Role of healthcare provider after the procedure
Experience related to effective pain management skills by self	Home remedies useful for pain management
	Use of pain relief medications

"I felt very anxious and satisfied at the same time. I have trust in doctors and nurses that they will make my grandson recover soon." (P4, father, 6 years old).

"My pain was more than my grandson's pain. I felt like crying. The needle has been piercing me in my heart when the needle was being adjusted again and again in that little hand." (P5, mother 4 years old).

"I was anxious, I cried a lot on the phone while talking to his dad." (P9, mother, 6 years old).

"I felt like its paining at my hand site." (P10, father, 6 years old).

Most of the children experienced pain for 5-10 minutes, while a few participants' pain lasted for half an hour and very few children did not felt any pain during and after the procedure.

"My child didn't express any pain." (Pt code 8, 9, 12, and 13).

"My child was in pain for about an hour." (P2, mother 6yrs old).

Most of the children were not ready to perform the procedure, and the general reaction of the children toward

the nurses was very bad, they didn't allow the nurses to come near them.

"My baby was playing when nurses came in the procedure room, My baby understood that the procedure was going to be painful, so she didn't want to let the procedure happen, She started telling bad sister, No need to do, a bad sister she hurted me." (P3, mother, 3 years old).

"After the procedure, he doesn't want to see any nurse, he was very jolly before the procedure." (P5, mother, 4 years old)

Most of the children were very anxious, nervous and disturbed after the procedure, they developed healthcare provider fear and didn't want any doctors and nurses around them.

"My baby was very disturbed and was in much pain, he kept on telling mummy to help me, it's hurting me a lot." (P1, mother, 5 years old).

"Baby was anxious, nervous, and afraid he avoids the doctors and nurses being around." (P9, mother, 6 years old).

"My child kept on saying aiyaa bho, leave me." (P8, mother 3 years old).

"My baby was anxious, started hitting the ward sisters, and said don't come near me." (P6, mother 4 years old).

To summarize parents are more anxious and nervous than their children during painful procedures, many parents feel that why god has given this pain to their children, if I could bear my child's pain it would be very helpful for my child. Children after the procedure were more afraid of the white coat personnel in the hospital, they didn't want any nurses and doctors to be around them.

Theme 2: Experience related to means of distractions

This theme covers toys used during painful procedures, coping mechanisms of children, and communication and counseling by parents.

Most of the children didn't focus on the use of any toys. Some of the children had their favorite toys along with them which helped the parents to distract the child during the procedure, very few children performing the procedure without their toys were distracted by watching cartoons on mobile phones.

"I used my baby's favorite car while performing the procedure. I asked my baby to control her emotions and play with the car." (P6, mother 4 years old).

"I used a mobile phone to distract my child." (P3, mother 3 years old).

Most of the children coped with the painful situation by looking at their parent's instructions and having faith in their parent's words.

"I kept stroking the child, I asked him to look up, look there look here, and he got distracted easily from pain." (P7, mother 4 years old).

"I told my baby to look at me, it pains like a small insect bite. My baby becomes blissful when I am around. She is very attracted towards me." (P2, mother, 6 years old).

Many parents also confirmed that counseling and talking to their child during the painful procedure reduces the anxiety level of the child and helps in easy distraction of the child. Some of the children were also convinced by getting chocolates as a reward for the successful procedure.

"Don't look at the needle. You will recover soon after the procedure." (P12, father, 6 years old).

"I told my son that it won't hurt much. This procedure is necessary to be healthy as soon as possible." (P4, father, 6 years old).

"I counseled my child that it is for your good, and he understands." (P1, mother, 5 years old).

"I told my baby I will give you more chocolates." (P8, mother, 3 years old).

To summarize children are very easily distracted by making them think about something they like most, playing with their favorite toys, watching cartoons, and promises to give their favorite food by their parents or nurses. Children can be counseled to let the procedures happen smoothly by providing them with rewards.

Theme 3: Experience related to the role of the healthcare provider

This section covers an adequate explanation of the procedure, parental expectations towards the procedure, and the role of the healthcare provider after the procedure. Most of the parents were satisfied with the health care professionals' effort towards making the parents understand the procedure, some of the parents also expressed that they are not well educated so they cannot understand the medical terms and understand about medical procedures.

"Nurses just said it might pain a little, and I understood. I agreed with what they said, actually. We are unaware of the procedure in detail." (P5, mother, 4 years old).

"Nurses explained about the procedure superficially. I felt it was fine, I don't need much information." (P10, father, 6 years old).

Most parents expect health professionals to hold their child, counsel their child, and play along with their child. Almost all the parents were seeking the procedures to be done by experienced nurses only.

"Health care workers should provide real information in detail. They would do whatever is best for my child. Parents also request that please perform cannulization by experienced staff rather than the trainee or the student nurse." (P5, mother, 4 years old).

"Parents verbalize we are satisfied with whatever information has been provided by staff. Pt says if we were more educated like you, then only it would be necessary for us to have more information." (P10, father 6 years old).

"Parents say rather than focusing on the procedure nurses should be in the group and entertain the child, distract the child while performing cannulization." (P13, mother, 6 yrs old).

Most of the parents expected the nurses to be present every time by their bedside and along with their child, assessing the child's progress, pain and procedures.

"Parents always expect the nurses to be around their child, monitoring their child's progress and recovery from pain." (P11, mother 4 years old).

"Nurses take care of many children every day. They know all the techniques to counsel the child. It would be much helpful for us if they would help us counsel our child." (P1, mother, 5 years old).

To summarize nurses' level of explanation about the procedure to the uneducated parents was not adequate, parents expected each nurse to be always present with them, and only perfect and well-experienced nurses should perform any procedures on their child.

Theme 4: Experience related to effective pain management skills by self

This section covers experiences related to home remedies useful for pain management, and the use of pain relief medications

Almost all the parents verbalized that using Ice packs in the area of pain and warm oil massage is very helpful in relieving swelling and pain in the younger child.

"Massaging with warm oil in the area where there is pain would be very useful to the child." (P3, mother 3 years old).

"Using Ice packs during cannulization is a very traditional way of treating swelling and pain for the child." (P14, mother, 4 years old).

"I often use hot water therapy, hot oil massage in whichever site my baby is in pain." (P6, mother, 4 years old).

Most of the parents expressed that the use of pain relief medication is not safe for children below 5 years, some of the parents said that they sometimes use pain relieving medication such as DFO gel, Moov, and Diclofenac gel in mild pain.

"Use of local pain relief medication can be useful in managing pain in children." (P2, mother, 6 years old).

"I use anti-pain cream for my child." (P12, father, 6 years old).

"I give DFO gel when my child complains of pain." (P9, mother, 6 years old).

To summarize Almost all parents used warm oil massage in relieving their child's pain, and very few parents had experience of using pain medications in their child.

DISCUSSION

The present study had explored the lived-in experience of parents related to procedural pain in children during hospitalization.

The result of the present study was nearly similar to the findings of this study done by Shave in Alberta Stollery Hospital that showed 75% of participants were mothers, 42% were between the ages 30-35 years, and 50% were between 36-41 years, 50% had visited the hospital in 0-4 months, 42% of children were admitted in hospital once, 55% had an intravenous insertion in between 2-5 times.¹⁹

The result of the present study showed parental anxiety and nervousness while the child was undergoing any painful procedures. Most of the parents were scared before the procedure but after sometime they got adjusted to the situation, maybe because of the awareness about the need for the procedure, the hospital environment, and the trust towards the healthcare professionals.

P2 mother (6 years old) shared about the emotional problem of her baby, *"my baby is extremely afraid of boys, I didn't notice it during her early childhood, later she even gets scared of his father and every male person in the house and started avoiding them, I need to consult the psychiatrist here"*.

Parents also shared some bitter experiences related to medical practice while doing the cannulization, the needle of the cannula was bent due to the force exerted by the health care providers.

One of the parents also suggested that don't make the child look at the needle and procedure unless the child can understand what and why it is being done and says

"My child always says Namaste and bye-bye to all the nurses." P6 (mother 4 years old).

P7 shared her feelings "My child is very rigid in nature, he is very irritable shows tantrums every now and there, he keeps getting angry always, he is poor in writing skills but good in reading, is it because of his illness or is it his actual personality?"

P8 shared her experience related to health care professional's effect "I and my child's feelings related to pain had gone after the nurses spoke to us softly."

P9 showed sadness by saying "my child is very mature according to her age. she is mostly dependent on her father, so she doesn't share her feelings with me. I don't know is she fine or is it paining her much now?".

The present study was also supported by the study done in Finland on parent's perception of their child's pain assessment during hospitalization which reported that most children experience moderate to severe pain during hospitalization. Parents were often involved in pain assessment but were rarely instructed to use pain scales. They lacked adequate guidance from healthcare professionals about how to assess the level of pain in their children.¹³

Some of the parents in the present study said "I am not able to understand what my child is actually feeling during hospitalization. He always says it's aching badly in my hand but I am not getting adequate guidance from health workers regarding the level of pain my child is suffering."

The result of the study was also supported by the study done in Edmonton Alberta Stollery Hospital which reported there were core information needs for caregivers whose children were experiencing IV insertion or venipuncture. The same study also reported that the themes developed were based on the source of health care information, information needs, delivering information, and communicating about the painful procedures with parents are seen as helpful in managing stress and anxiety among parents and children during hospitalization.¹⁹

The result of the present study was also supported by the study done by Kammerar on the pain experiences of children and their parents at a Canadian children's hospital which reported that parents had expectations from the health workers to actively take care of their child's pain so that the child had positive memories from the hospital stay.²⁰

The report of the study done in Alberta Stollery Hospital regarding parental experience with procedures was similar to this study which reported parents' negative experiences with painful procedures for their children, occurring mainly at non-pediatric centers.¹⁹ In this study P6 parent mother 4 years old shared her negative

experience while doing intravenous insertion was very painful and traumatic for the child when performed in clinic and health post.

This study provided the lived-in experience of parents towards procedural pain in their children and the various dimensions related to the process, the role of health care providers, and the method used to ease the pain during the process. This was a novel study that used the qualitative research design to explore the dimensions of lived-in experience in pediatric settings in Nepal.

Since it was a qualitative study the experience of these limited participants may not be represented to all the other people of the study setting. The experience may vary depending on the age group, time duration, facilities of the hospital, knowledge of healthcare workers, and attachment of the parent dyads with their children.

CONCLUSION

Parents had to deal with anxiety and nervousness related to painful procedures performed on their children. Most of the participants expressed satisfaction with the efforts of health workers and their explanation for adequate preparedness during painful procedures. Moreover, some participants suggested the involvement of nurses in pain management. Parents expected the nurses to distract their children during the invasive procedure through a competent yet gentle approach. There is a need for a proper explanation of the procedures, its importance, and postprocedural pain management. The provision of play therapy in a hospital setting is required to minimize the pain and stress related to painful procedures and hospitalization as well.

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