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PARENTS’ UNDERSTANDING OF INFORMATION REGARDING THEIR CHILD’S POSTOPERATIVE PAIN MANAGEMENT

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Abstract

Objectives—Unlike information provided for research, information disclosed to patients for treatment or procedures is largely unregulated and, as such, there is likely considerable variability in the type and amount of disclosure. This study was designed to examine the nature of information provided to parents regarding options for postoperative pain control and their understanding thereof.

Methods—187 parents of children scheduled to undergo a surgical procedure requiring inpatient postoperative pain control completed questionnaires that elicited information regarding their perceptions and understanding of, and satisfaction with, information regarding postoperative pain management.

Results—Results showed that there was considerable variability in the content and amount of information provided to parents based on the method of postoperative pain control provided. Parents whose child received Patient Controlled Analgesia (PCA) were given significantly ($P < 0.025$) more information on the risks and benefits compared to those receiving Nurse Controlled or intravenous-prn (NCA or IV) analgesia. Approximately one third of parents had no understanding of the risks associated with postoperative pain management. Parents who received pain information preoperatively and who were given information regarding the risks and benefits had improved understanding compared to parents who received no or minimal information ($P < 0.001$). Furthermore, information that was deemed unclear or insufficient resulted in decreased parental understanding.

Discussion—These results demonstrate the variability in the type and amount of information provided to parents regarding their child’s postoperative pain control and reinforce the importance of clear and full disclosure of pain information, particularly with respect to the risks and benefits.

Keywords

Informed consent; pain management; postoperative; risks; benefits

INTRODUCTION

Informed disclosure of information is an important pre-requisite for most non-emergent medical procedures and treatments. However, studies have shown that even after full disclosure of information, many parents and children have inadequate understanding of the risks, benefits, and alternatives for research or treatments.[1–3] Furthermore, in anesthesiology

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practice, provision of information in busy, stressful settings such as preoperative waiting areas, may lead to poor understanding if parents and children are given insufficient time to review the information or to ask questions. Although there are a few studies that have examined parents' preferences for information regarding anesthesia[4–6] and the effects of this information on parents' anxiety,[7–9] there is a paucity of data regarding parents' informational requirements regarding postoperative pain management. This study, therefore, was designed to evaluate parents' perceptions of the nature, timing, adequacy, and understanding of information given to them regarding options for their child's postoperative pain control. It is hoped that findings from this study will be important in identifying areas of concern and in developing strategies to improve the manner in which such information is presented and understood.

MATERIALS AND METHODS

The University of Michigan's Institutional Review Board approved this study with a waiver of written informed consent. The study population included parents of children (birth-17 yrs.) undergoing elective surgical procedures requiring inpatient postoperative pain management involving Patient Controlled Analgesia (PCA), Nurse Controlled Analgesia (NCA), or Intravenous-prn analgesia (IV). Following the child's surgery, parents were given a questionnaire to elicit information regarding their perceptions and understanding of the risks, benefits, and alternatives for their child's postoperative pain control.

The questionnaire contained closed-ended questions requiring categorical scale responses. Provision was also made to allow for parents to expand upon or explain certain responses. The questionnaire included 42 items divided into five sections, as follows:

1. *"Information about pain control options"*: items in this section dealt with the type of primary pain control that the child received, whether or not different pain options were offered, whether the child was given any information, who gave the information, and whether or not the risks, benefits, and management of side-effects were discussed. Measures of satisfaction were measured on a 5-point scale of "extremely dissatisfied" to "extremely satisfied." Parents' perceived understanding of the information was measured using 0–10 numbers scales, where 10 = "understood completely." Parents' understanding of the likelihood and potential severity of side-effects (e.g., nausea and vomiting, itching, sedation, constipation, slowed breathing, and poor pain control) were measured using categorical scales of "rarely," "often," "always" and "not severe," "serious," "life-threatening," respectively. A category of "not sure" was also included.
2. *"Decision-making"*: items in this section sought information regarding who made the decision regarding the choice of primary pain control, whether or not the parent and/or child were involved, satisfaction with their involvement in decision-making, and whether enough time was provided to make a decision.
3. *"Child's postoperative pain experience"*: Parents were asked to list any side-effects experienced by their child and whether these side-effects were "less than expected," "the same as expected" or, "worse than expected." The maximum pain experienced by the child was scored using a 0–10 numbers scale where 10 = "worst pain ever."
4. *"Preferences for pain control information":* Parents were asked if the information that they had been given was "too little," "just right" or, "too much." If parents perceived the information as too much or too little, they were asked what information they would have preferred to have, or have not, received. Other items

dealt with how parents prefer to receive information about postoperative pain control.

5. *“Demographics”*: This section elicited information regarding the child’s age, gender, and health status (0–10 scale, where 10 = extremely healthy), previous experience with postoperative pain control, race/ethnicity, level of education, and household income.

In developing the questionnaire items were first shown to **5** parents to assess face validity i.e., how well an item or set of items appeared. Similarly, 5 investigators with experience in pain management were shown the questionnaire for an informal assessment of content validity. Items that were considered ambiguous or confusing were reworded or discarded.

Statistical Analysis

Statistical analyses were performed using SPSS® statistical software (SPSS Inc, v 14.0, Chicago, IL). Descriptive data were analyzed using frequency distributions. Comparisons of non-parametric data were performed using Chi-square and Fisher’s Exact test, as appropriate. Data are presented an n (%) and mean ± SD. Significance was accepted at the 5% level ($P< 0.05$). We estimated that there would be approximately 850 cases requiring postoperative opioid pain management during the study period. Using standard survey methodology, the sample size was large enough to provide a representative sample with a confidence level of 95% and a confidence interval of ± 6%.

RESULTS

A total of 272 parents whose children had undergone a surgical procedure requiring postoperative IV opioids for pain control were approached 24–72 hours after surgery to participate in this study. Of these, 5 parents declined to participate, 13 children were excluded due to a change in their primary pain management e.g., epidural or oral medications only, and 67 did not return or complete the questionnaire. Data are thus presented for 187 parents. The demographics of the study sample by primary postoperative pain control method are described in table 1. Children who received PCA were, not surprisingly, significantly older than children receiving other pain control options ($P< 0.001$). Table 2 describes the information provided with respect to the use of PCA, NCA, or IV analgesia as the primary postoperative pain management option. Parents of children who received PCA were given significantly more information than those receiving either NCA or IV ($P< 0.025$). In particular, there was a greater amount of discussion regarding the benefits and potential side-effects of PCA compared to NCA and IV. Of concern was the fact that overall, 66.8%, 54.3% and 65.4% of parents received no information preoperatively regarding the benefits, risks and management of side-effects, respectively. Parents of children who received PCA were significantly more satisfied ($P< 0.01$) with the information provided than parents whose child received an IV-prn medication for pain control. Although the majority of parents overall (77.2%) were satisfied with the information provided, reasons for dissatisfaction were primarily related to a perceived lack of information or discussion. Significantly more children were given information about PCA than for NCA or IV (68.1% vs 34.5% vs 22.2%, respectively, $P< 0.025$). Of those children receiving PCA, 54.2% were not given information because they were considered too young (mean age 5.6 ± 4.6 yrs) and 25% were simply not offered any information. This is important given that 51.3% of the parents whose child was not told about PCA would have preferred that their child had received information about its use.

The parents’ perceived understanding with respect to the type of information provided is described in table 3. There were no differences in understanding by race/ethnicity or education level. However, parents who were provided with pain information preoperatively or who were given details of the risks and benefits of the different pain options perceived their understanding as significantly ($P< 0.001$) greater than those who did not receive this information. Interestingly, parents who did not receive information about the potential risks of their child's pain management were more likely to perceive their child's side-effects as "worse than expected," compared to those who had received risk information (23.9% vs 14.3%, $P < 0.05$). Information regarding pain management was typically (56.3%) provided by more than one individual including nurses, anesthesiologists and surgeons. However, in 24% of the cases, an anesthesiologist supplied the information alone. There were, however, no differences in parents' perceived understanding with respect to who gave the information.

Parents who perceived the information as "very clear" had significantly greater understanding than those who perceived the information as "not clear" (8.8 ± 1.3 vs 2.2 ± 1.8, $P < 0.001$). Similarly, parents who perceived the amount of information as being "just right" had greater understanding than those who perceived the information as "too little" (8.4 ± 1.8 vs 5.0 ± 1.8, $P = 0.001$). Comments from parents who perceived that the information was too little included "… more information about side-effects and how they would be handled," and "… more information provided preoperatively." An additional finding was that parents who were involved in the decision-making process had greater understanding than those for whom the decision was made by the physician alone (8.5 ± 1.8 vs 7.0 ± 2.7, respectively, $P <0.001$). Furthermore, of those parents who were involved in the choice of pain management, 6% felt as if they had insufficient time to make a decision. Interestingly, these parents had significantly less understanding than parents who believed that they had sufficient time to decide (8.4 ± 1.6 vs 5.2 ± 3.7, respectively, $P = 0.007$)

Overall, parents perceived the risks of each pain option to be relatively low, yet were similar between groups. On a 0–10 numbers scale (where 10 = extremely risky), the perceived risks of PCA, NCA, and IV were 3.7 ± 2.6, 3.8 ± 2.5, and 4.1 ± 2.5, respectively. Although, there were no differences between groups with respect to parents' understanding of the risks and severity of individual side-effects associated with pain medications, up to one third of all parents had no understanding of these important elements (table 4).

Table 5 describes the involvement of parents and children in decisions regarding the choice of different pain options. Parents were significantly more involved in decisions regarding PCA and NCA than for IV, and children were more involved if they received PCA ($P< 0.025$). Although many children were too young to participate in decision-making, many parents voiced that they would have preferred greater involvement of their children in the decision-making process. Of those parents who were involved in the decision-making process, 81.7% stated that they considered the risks and benefits when reaching a decision.

Table 6 describes the parent-reported side-effects experienced by their children in each of the pain management groups. Twelve percent, 14.8% and 20.3% of parents in the PCA, NCA, and IV groups respectively perceived these side-effects to be "worse than expected" (IV vs PCA, $P = 0.05$). Although the majority of parents were satisfied with their overall child's pain management, a disturbingly high percentage of parents whose children received NCA were "extremely dissatisfied" (17.9% vs 3.3% and 1.6% for PCA and IV, respectively, $P<0.005$)). Despite this, however, most parents reported that they would choose the same pain option again if needed (93.3% PCA, 81.5% NCA, 83.6% IV).

DISCUSSION

Although several studies have addressed patients' informational needs regarding anesthesia and their understanding thereof, there is a paucity of similar information related to postoperative pain management, particularly as it pertains to children. Kain et al. explored parents' desire for perioperative and anesthetic information and found that 95% wished to receive comprehensive information including the risks of anesthesia.[4] Other studies have reinforced these findings. In one study, Wisselo et al. showed that 55% of parents sought more extensive information regarding anesthesia for their child,[6] and in another, Waisel and Truog found that 90% of parents desired specific information related to anesthetic risk.[10] In terms of pain management, Walker et al. surveyed several London hospitals and found that while 80% reported providing procedure specific information on adult pain management, detailed information about postoperative pain care was poorly described.[5] Furthermore, in a study of the risks associated with regional anesthesia for childbirth, up to 94% of patients desired information regarding common, less severe side effects, and as many as 77% wanted to know about rarer, but more severe complications.[11] In addition, the anesthesiologists in this study were shown to differ widely in what risk information they believed patients needed in order to consent to epidural analgesia. This is important as studies have shown a disconnect between what information physicians believe is important to disclose and what information patients or parents actually want.[12, 13] A previous study from our institution showed that physician-investigators differed significantly with parents regarding the information they thought was most important for decision-making[13] and thus highlights the importance of disclosing information that meets the informational needs of the parent or patient.

Results from this study showed that important elements such as the risks, benefits and management of side-effects were discussed in less than half of the cases. Furthermore, the degree of disclosure varied with the choice of primary pain management. For example, approximately one half of patients receiving PCA and only one third of those receiving NCA or IV were told about the risks of side-effects. This is important in light of the observation that parents who received information about the benefits, risks, and management of side-effects had significantly greater perceived understanding than those who did not. Additionally, since unauthorized PCA by proxy (i.e., dosing by a family member or caregiver) has been associated with over-sedation and adverse respiratory events,[14] it is imperative that parents are fully informed about the risks when PCA or NCA are implemented. The observation that 25% of children deemed old enough were not given any information about PCA is disturbing since a lack of understanding may affect their ability to manage their pain control postoperatively.

Not surprisingly, results also showed that parents had greater understanding if they had been given specific information about pain management prior to surgery. In one study, preoperative preparation was found to be most useful when given 5–7 days prior to surgery[6] and in another, preoperative anesthetic information for children administered via leaflet or video was shown to decrease parental anxiety[4, 7, 8] and increase satisfaction[7] and knowledge.[8] In our setting, the majority of parents and some children are given information on the day of surgery, while a smaller percentage are seen by a nurse or physician several days to 2 weeks prior to surgery.

In addition to the importance of disclosing the details of a particular treatment or procedure, is the manner in which it is presented. Studies have shown that parents' understanding of consent information and their perceptions of risk and benefit are correlated with the perceived amount and clarity of the information.[15, 16] Although not directly relevant to acute postoperative pain information, Muss et al. showed that understanding of chemotherapy regimens was greatly enhanced by the clarity of the information.[17] Furthermore, a previous study from our institution found that a research consent presented on the day of surgery when parents are typically anxious, was better understood when the information was deemed clear by the parents.[16] Our current study supports these findings wherein information that was deemed "very clear' or "just the right amount" was better understood by parents than those who perceived the information as unclear or incomplete. In our setting, very little information regarding postoperative pain control is presented in written form, yet 49% of parents reported that they would prefer both verbal and written information. This may explain why approximately one third of parents had no understanding about the risks and benefits of postoperative pain control.

The importance of parental or patient understanding cannot be overstated since a lack of understanding can result in the misinterpretation of the risks and benefits and the inability to follow a treatment regimen. Griffin et al. examined the contribution of intensive preoperative education on outcomes related to PCA use in adults and found that although PCA education did not affect pain scores, morphine consumption, or satisfaction, it did result in earlier and more effective use of antiemetic medication.[18] Several studies have shown that many parents and patients have incomplete understanding of consent information for both research and clinical care.[2, 19, 20] In one study, Cassileth et al. showed that while 85% of cancer patients claimed to understand the information presented, only 55% could list one major complication of chemotherapy.20 Perhaps, more alarmingly, Byrne et al. showed that as many as 27% of surgical patients did not know which organ had been operated on.[19] The ethical and legal implications of these findings are evident. It is thus imperative that physicians take time to ensure that parents (or patients) are fully informed and that they understand the information provided. This can be accomplished by providing complete information at a level consistent with the parents' abilities, allowing time for questions, and confirming their understanding by asking them to paraphrase the information or reiterate important points.

In this study, parents were involved in decisions regarding their child's pain management in approximately half of the cases. This is interesting in light of a study by Strull et al. which showed that physicians substantially underestimate their patient's desire for information and overestimate their interest in decision-making.[12] Active engagement of patients in decision-making has been shown to improve understanding, patient satisfaction, self-esteem, and outcome[21, 22] although some would argue that patients prefer the paternalistic approach of "doctor knows best." [23, 24] In our study, active involvement of parents in decision-making appeared to be helpful as a means to enhance their understanding of the information. Although we recognize that decision-making involves a number of other variables including decisional uncertainty and coping style, we believe that this information is worthy of consideration when giving information to parents regarding postoperative pain management.

The potential limitations of survey research include non-response, recall, and self-report biases. Given that the parents filled out the questionnaires "in house," non-response was relatively low. Furthermore, since all questionnaires were completed anonymously (i.e., contained no identifying information), the potential for parents to deliberately embellish or withhold information to avoid any concerns over the care of their child was likely minimal. While we cannot rule this out, any self-report bias should have affected all groups equally. Recall bias was similarly unlikely since the parents completed the questionnaires just after their child's surgery. Two other potential limitations deserve mention. First, parental levels of understanding were based on their perception rather than independent assessment. Previous studies have shown that parents (and children) tend to over-estimate their understanding of consent information,[2, 3, 7, 25] thus, the levels of understanding reported by the parents in this study are likely higher than their "true" understanding. Nevertheless, the results show that understanding is influenced by several factors related to the quality and amount of the disclosed information. Finally, this study reflects the practices of a single hospital and, as such, may not be generalizable to all institutions.

The results of this study suggest that disclosure of information regarding postoperative pain management, and parents' understanding, thereof, are variable and often incomplete. As proxy decision-makers for their children, parents are responsible for making decisions that are in the best interests of their child. Thus, in order to ensure that parents can protect these interests, it is imperative that they are given sufficient information, presented in a manner consistent with their informational needs and health literacy, and which optimize their informed understanding and decision-making.

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Table 1

Demographics by Choice of Primary Pain Management

	PCA **(n = 95)**	**NCA** **(n = 29)**	**IV** **(n = 63)**	**All** **(n = 187)**
Child's age (yrs)	11.6 ± 4.2	6.1 ± 5.0[†]	4.3 ± 4.3[†]	8.1 ± 5.5
Parents' age (yrs)	40.0 ± 6.7	36.2 ± 8.7	33.0 ± 6.6	36.7 ± 7.7
Gender (M/F)	45/55	36/64	58/42	47/53
Race/ethnicity:				
Caucasian	88.9	85.2	82.3	86.4
African American	7.8	0	8.1	6.3
Other	3.3	14.8	9.6	7.3
Education Level:				
≤ High school graduate	21.1	29.6	31.1	25.8
Some College	36.7	29.6	31.1	33.7
≥ College graduate	42.2	40.7	37.7	40.4
Prior surgery	65.2	66.7	67.7	66.3
Child's health[*]	8.5 ± 1.7	8.4 ± 1.5	7.9 ± 1.8	8.3 ± 1.7
Surgical Service:				
Orthopedics	68.9	53.6	13.3	45.5
Cardiac	12.2	14.3	50	24.1
Pediatric surgery	16.7	21.4	25.0	19.3
Otolaryngology	0	3.6	8.3	3.2
Other	2.2	7.1	1.7	2.7

PCA = Patient controlled analgesia, NCA = Nurse controlled analgesia, IV = Intravenous analgesia

[†] P<0.001 vs PCA

[*] Parental perception based on a 0–10 scale where 10 = extremely healthy Data are presented as % and mean ± SD

Table 2

Information Regarding Pain Management Options[**]

	PCA	NCA	IV	All
Different options discussed	65 (69.9)	20 (69.0)	34 (54.8)	119 (64.7)
Benefits discussed	45 (47.4)[*†]	6 (20.7)	11 (17.5)	62 (33.2)
Side-effects discussed	52 (54.7)[†]	11 (37.9)	22 (35.5)	85 (45.7)
Management of side-effects discussed	40 (43.0)[†]	8 (29.6)	14 (23.7)	62 (34.6)
Somewhat/extremely satisfied with information	82 (88.2)[†]	22 (78.6)	38 (60.3)	142 (77.2)
Understanding[‡]	8.1 ± 2.1	6.9 ± 3.3	7.6 ± 2.2	7.7 ± 2.4

Data are presented as n (%) or mean ± SD

PCA = Patient controlled analgesia, NCA = Nurse controlled analgesia, IV = Intravenous analgesia

[**] % based on number of parents who responded

[‡] Based on a 0–10 scale where 10 = complete understanding

[*] P <0.025 vs NCA

[†] P. <0.01 vs IV

Table 3

Parents' Perceived Understanding of the Pain Information Provided

	Understanding[*]	
	Information given "Yes"	**Information given "No"**
Preoperative pain information	8.0 ± 2.0	3.5 ± 3.4[†]
Pain options	8.4 ± 1.7	6.6 ± 3.1[†]
Benefits of primary pain option	8.9 ± 1.5	6.5 ± 3.0[†]
Risks of primary pain option	8.5 ± 1.7	6.7 ± 3.1[†]
Management of side-effects	8.8 ± 1.3	6.7 ± 3.1[†]

[*] On the basis of a 0–10 scale where 10 = complete understanding

[†] $P \leq 0.001$

Table 4

Percentage of Parents with no Understanding of the Risks and Severity of Potential Side-effects[**]

	No Understanding (%)	
Side-effect	**Risks**	**Severity**
PONV	38 (22.5)	25 (15.2)
Itching	45 (27.8)	32 (22.2)
Sedation	26 (15.3)	25 (15.7)
Constipation	52 (31.2)	38 (24.4)
Respiratory depression	57 (34.5)	33 (20.9)
Poor pain control	61 (38.4)	37 (22.8)

PONV = Postoperative nausea and vomiting

[**] % based on number of parents who responded

Table 5

Parent and Child Involvement in Decision-Making[**]

	PCA	NCA	IV	All
Parent involved	50 (52.6)[*]	18 (64.3)[*]	21 (33.3)	89(47.8)
Child involved	40 (42.1)[*]	6 (21.4)	7 (11.1)	53 (28.5)
Parent wanted more child involvement	14 (14.9)	5 (20.0)	10 (17.9)	29 (16.6)
Extremely satisfied with pain care	45 (49.5)	14 (50.0)	20 (32.8)	79 (43.9)

PCA = Patient controlled analgesia, NCA = Nurse controlled analgesia, IV = Intravenous analgesia

[**] % based on number of parents who responded

[*] P<0.025 vs IV

Table 6

Parent Reported Side-effects Experienced by their Children Postoperatively[*]

	PCA	**NCA**	**IV**	**All**
	(n = 95)	**(n = 29)**	**(n = 63)**	**(n = 187)**
PONV	48 (50.5)	8 (27.5)	20 (31.7)	76 (40.6)
Sedation	63 (66.3)	17 (58.6)	44 (69.8)	124 (66.3)
Respiratory depression	23 (24.2)	4 (13.8)	15 (23.8)	42 (22.5)
Itching	38 (40.0)	7 (24.1)	25 (39.7)	70 (37.4)
Poor pain control	14 (14.7)	3 (10.3)	10 (15.9)	27 (14.4)

PCA = Patient controlled analgesia, NCA = Nurse controlled analgesia, IV = Intravenous analgesia, PONV = Postoperative nausea and vomiting

[*] % based on number of parents who reported side-effects