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Children's Desire for Perioperative Information

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Abstract

Background—The purpose of this investigation was to identify what perioperative information children want to be given by the medical staff.

Methods—As a first step we developed an instrument based on a qualitative study conducted with children in Great Britain, input from a focus group, and input from school children. On the day of surgery, 143 children aged 7-17 years old completed a 40-item assessment of desired surgical information and a measure of anxiety (STAIC). Parents completed a measure assessing their child's temperament (EASI), and a measure of their own anxiety (STAI).

Results—Results indicated that the vast majority of children had a desire for comprehensive information about their surgery, including information about pain and anesthesia, as well as procedural information and information about potential complications. The most highly endorsed items by children involved information about pain. Children who were more anxious endorsed a stronger desire for pain information and lesser tendency to avoid information. Younger children wanted to know what the perioperative environment would look like more than adolescent children.

Conclusions—We conclude that the majority of children aged 7-17 years old who undergo surgery want to be given comprehensive perioperative information and healthcare providers should ensure adequate information regarding postoperative pain is provided.

Introduction

Studies in the United States and Europe have shown that many patients are dissatisfied with the amount of perioperative information they receive from physicians.¹⁻³ The desire for information among parents of children undergoing surgery is particularly strong because parents are frequently more concerned with their child's health than with their own^{4,5} and desire comprehensive perioperative information.⁶⁻⁸ Moreover, when provided with highly detailed anesthetic risk information, parents do not report increases in anxiety⁶ and parents

who received comprehensive preoperative information report significantly less anxiety than parents who received minimal information.⁹

There is paucity of data, however, regarding children's desire for perioperative information in spite of the fact that most preoperative preparation programs are based on provision of information for children. While many preparation programs exist, few are based on empirical evidence of what type of information is provided, the manner in which it is provided, and how children perceive such information.¹⁰ In particular, identification of what perioperative information is desired by children is vital information to the designs of preoperative preparation programs. Indeed, only one study was identified that specifically addressed this issue. In a British study involving nine children, Smith and Callery utilized qualitative interviews to identify specific preoperative information desire of children ages 7 to 11 years.¹¹ Children in this study indicated that they had not been directly provided information from healthcare professionals about their upcoming hospitalization and surgery and generated over 60 questions to be addressed about their admission. To our knowledge there has not been a larger scale study of children's desire for perioperative information in the operative setting. Thus, this study identifies specific preoperative information which is of importance for children undergoing surgery.

Methods

Participants

Participants were 143 healthy (ASA I or II) children ages 7-17 years undergoing outpatient, elective surgery and general anesthesia. Children with developmental delays or who did not speak English were excluded from this study. Parents and their children were recruited from two large children's hospitals: 96 (68%) children from Yale-New Haven Children's Hospital in Connecticut and 47 (32%) children from Children's Hospital of Orange County (CHOC) in California. Families were contacted by telephone prior to the day of surgery or on the day of surgery in the preoperative holding area. The Yale University Human Investigation Committee and CHOC Investigational Review Board approved this study, all parents provided written permission and consent, and children provided written assent. Baseline characteristics of the sample are shown in Table 1.

Measures

We would like the readers to note that all instruments administered in this study had reliability and validity values that range from 0.71 to 0.93. These values are considered good to excellent in the psychometric literature. Also, all instruments were administered by research assistants who had strong backgrounds in behavioral sciences.

Children's Desire for Information (CDI)—This measure was designed for the current study to examine children's interest in specific items of preoperative information. Items from Smith and Callery's qualitative study¹¹ were reviewed by a group of healthcare providers (representing pediatric anesthesiology, clinical psychology, developmental pediatrics, child life, and nursing). This group eliminated items that were deemed irrelevant to practice in the United States and added additional relevant items. The new measure was reviewed by a convenience sample of three classes of children aged 7-15 in schools in urban Connecticut. Based on their input, additional items were added, omitted, or modified.

The final measure was comprised of 40 items rated using a four-point scale: -1 = *I don't want to know*, 0 = *I don't care*, 1 = *I might want to know*, and 2 = *I really have to know*. A desire for information score was calculated by summing scores on items children endorsed with a 1 (*I might want to know*) or 2 (*I really have to know*). Information avoidance scores

were calculated by summing items that children endorsed with a -1 (*I don't want to know*). Finally, a total CDI score was calculated by summing responses to all 40 items. The overall 40-item measure demonstrated excellent internal consistency of 0.93 as measured by Cronbach's alpha. This statistic is commonly used as a measure of the internal consistency reliability of a psychometric instrument. Cronbach's alpha is a statistic to indicate how well a set of items measures a single construct.¹² Smith and Callery proposed several subscales of items in their initial study; we included only those in the present study for which the internal consistency reliabilities were acceptable. These consisted of: information regarding the overall perioperative procedures (*General Procedures* – 9 items; e.g., “What is going to happen?”, “What will they do to me?”); information regarding timing of events (*Timing* – 6 items; e.g., “How long will I be in the operating room?”); items regarding the anesthesia procedures (*Anesthesia* – 4 items; e.g., “How will they put me to sleep?”); information regarding the hospital and OR environment (*Environment* – 3 items; e.g., “What does the operating room look like?”); and items related to pain or nausea (*Pain* – 7 items; e.g., “Will I feel any pain?”). Internal consistencies for the subscales are as follows: General Procedures = 0.78; Timing = 0.71; Anesthesia = 0.72; Environment = 0.72; and Pain = 0.86.

Child Temperament: EASI Temperament Survey—This standardized tool is completed by parents and assesses children's temperament using 20 items in four behavioral categories: Emotionality, Activity, Sociability, and Impulsivity.¹³ Higher scores indicate higher temperament scores in each of the behavioral categories. The range of scores is 5 to 25. Reliability and validity of the EASI is acceptable.^{13,14}

Child Anxiety: State-Trait Anxiety Inventory for Children (STAIC)—The STAIC is a 40-item self-report measure of both state (situational) and trait (baseline) anxiety in children. The STAIC has good reliability and validity and is widely used to assess children's anxiety.¹⁵

Parental Anxiety: State-Trait Anxiety Inventory (STAI)—This self-report instrument assesses both state (situational) and trait (baseline) anxiety and is widely used.¹⁶ The STAI is well validated and has good reliability.¹⁶

Procedure

Following the consent procedures, children in both sites of this study completed all measures including the CDI in the preoperative holding area on the day of surgery. The measures were administered by research assistants who were present and available to answer any possible question regarding the study but not about the surgical and anesthetic procedures. Parents completed the EASI and STAI in the preoperative holding area as well. All study questionnaires were completed prior to the scheduled interaction between the patients and healthcare providers such as the anesthesiologists and surgeons. Parents completed demographic information once children were taken into surgery. All data collection took place in this location; therefore, study participation was concluded once the children completed the perioperative information questionnaire and parents completed all measures. The readers should note that most children and parents have been seen by surgeons prior to the day of surgery and it is likely that some anesthetic and surgical information was provided to the children and parents during that visit.

Data Analysis Strategy

Our sample size was based on preliminary data and the resulting assumption that about 95% of all children would desire the information presented to them. Thus, we assumed that $H_0: p \leq 94\%$, the alpha is 5.0% and the resulting sample size is 143 (http://www.netgm.com/netgm_tools/useful_stuff/questionnaire_sample_size.html).

Descriptive statistics were conducted to determine the percentage of children endorsing both desire for information and information avoidance. Relationships between child and parent characteristics (gender, age, temperament, anxiety) and desire for information, including total CDI score, desire for information, information avoidance and the 5 subscales (General Procedures, Timing, Anesthesia, Environment, and Pain) were examined using bivariate statistics. To determine any potential predictors of information desired, children were divided into two groups representing the upper and lower 25% of desire for information and information avoidance; analyses of variance (ANOVA) were used to examine the impact of group on demographics, including age, temperament, and anxiety. Significance was accepted at $p < 0.05$. Data were analyzed using SPSS 16.0 (SPSS Inc., Chicago, IL).

Results

Descriptive Analyses

A total of 143 children were enrolled in the study. Baseline characteristics of children and their parents are reported in Table 1. Analyses indicated there were no differences in individual items on the CDI between the two institutions (p values ranged from 0.19 - 0.98). Additionally, ANOVA and chi-square analyses revealed no significant differences on the demographic variables of child age ($p = 0.34$), parent marital status ($p = 0.19$), or family income ($p = 0.94$) across sites. There were also no differences across sites for the major study variables of CDI total score ($p = 0.59$) and subscales (p s ranged from 0.20 - 0.76), child trait ($p = 0.48$) or state ($p = 0.46$) anxiety (STAIC), parent trait ($p = 0.37$) or state ($p = 0.20$) anxiety (STAI), or child temperament (EASI) (p values ranged from 0.46 - 0.85).

The percentages of children who endorsed *I really have to know* on each item are shown in Table 2. The range of frequencies for *I really have to know* was 14% – 71.5% with over 40% of children endorsing really wanting to know 25 of the 40 items. As evidenced by Table 3, the five items most endorsed in the information desired category (identified by summing percentage of children who endorsed *I really have to know* and *I might want to know* for each item), children were overwhelmingly interested in information about pain. In terms of information avoidance (those items endorsed with *I don't want to know*), it is notable that these frequencies were very low. The most frequently endorsed item in this category was “Will I get a needle?” (19.1%). Less than 10% of children endorsed *I don't want to know* for 28 of the 40 items. Please refer to Table 3 for the five most endorsed items by children in the information desired and information avoidance categories.

Child Characteristics and Desire for Information

Relationships between children's characteristics (gender, age, temperament, anxiety) and information desired were first examined using bivariate correlations. There were no significant correlations among child gender, age, and temperament on desire for information, information avoidance, or on any CDI subscale scores. Conversely, significant correlations emerged for children's state anxiety and information avoidance and desire for pain information on the CDI. Specifically, children's state anxiety was negatively correlated with information avoidance ($r = -0.22$, $p = 0.02$) and positively correlated with desire for pain information ($r = 0.26$, $p < 0.01$). That is, children who were more anxious endorsed greater desire for information about pain and were less likely to endorse *I don't want to know* on items on the CDI. Children who had at least one prior surgery did not differ from children who had never had previous surgery in terms of the overall amount of information they desired ($p = 0.59$), information avoidance ($p = 0.64$), or in any of the different types of information, including pain ($p = 0.76$), general procedures ($p = 0.40$), timing ($p = 0.64$), anesthesia ($p = 0.69$) or environment ($p = 0.18$).

ANOVAs were used to examine demographic differences between children who desired a great deal (i.e., highest 25%) and a very little amount (i.e., lowest 25%) of information. No differences were found for desire for information based on age, gender, child state anxiety, child trait anxiety, parent state anxiety, or parent trait anxiety ($p > 0.05$). There were also no differences found for any of the child temperament scores on the EASI ($p > 0.05$). Similarly, ANOVAs were used to examine demographic differences between children who were highly avoidant (i.e., upper 25%) and not avoidant (i.e., lower 25%) in terms of information. No differences were found for information avoidance on any of the demographic variables noted above. However, when examining children based on those scoring above and below the mean on information avoidance, mean differences on state anxiety approached significance ($F(1, 116) = 2.96, p = 0.08$). That is, consistent with the correlational findings above, those children who scored lower on information avoidance on the CDI were those that were most anxious in the preoperative holding area.

Although there was no linear relationship between age and desire for information, we recognize that the current sample represented developmentally distinct periods of preadolescence and adolescence and thus, we evaluated differences in desire for information across these groups. Specifically, children were divided into two groups based on age (Preadolescence = 7 – 11 years and adolescence = 12 – 17 years) and ANOVAs were conducted to compare group differences on types of information desires. Younger children desired more information about the medical environment (e.g., “What does the operating room look like?” “What does the recovery room look like?”), $F(1, 114) = 8.02, p = 0.01$. No other statistically significant differences emerged between the two groups.

Discussion

Previous pediatric studies regarding preoperative information are largely limited to parents and only one small-scale British study elicited information desired by children themselves.¹¹ Building upon the small study in Britain, we were able to examine desire for perioperative information on the day of surgery using a large sample of children. In the present investigation, we found that the vast majority of children preferred to have comprehensive information concerning their surgery, including information about pain, anesthesia, perioperative procedures, and information about potential complications. Results also highlighted that children undergoing surgery most strongly desired information about pain, including whether they would experience pain, how long it would last, and how bad it would be. Additionally, we found that the more anxious children were, the more they desired information about pain specifically, and the less likely they were to want to avoid information. Preadolescent children were more interested in knowing what the perioperative environment would look like than were adolescents. Finally, we found that children with a history of previous surgery did not require less perioperative information as compared to children who never had surgery. Although surprising, this finding may indicate that children with a history of surgery were not adequately prepared for their previous surgeries or that these children have no memory of their past surgery.

Overall, the findings suggest that comprehensive information should be available to most children and healthcare providers ought to pay particular attention to ensuring children are provided adequate information regarding pain and that younger children are informed of what they will see in the surgical environment. In addition, we found that the most anxious children reported wanting the most information. That is, children endorsing more situational anxiety also scored higher on the CDI, indicating they more frequently endorsed items with *I really have to know* as well as fewer items with *I don't want to know*. It is likely that highly anxious children are seeking out information in attempts to manage their anxiety.

Until recently, parent's views have served as proxies for their children but there is now an increased awareness of the desire to listen to children.¹⁷ Indeed, the concept of patient-centered-care, the Children's Act 1989¹⁸, and the UN Convention On The Rights Of The Child¹⁹ all stress the importance of listening to children and considering their views when planning services and making decisions. The authors suggest, however that this also includes respecting the viewpoint of the minority of children who prefer not to have comprehensive information provided.

Several limitations of this study should be noted and addressed in future research. Children in our sample were relatively healthy and undergoing routine surgeries. Our sample size precluded analyses of the impact of type of procedure or past experience in medical settings (other than surgery history) on desire for information. Future studies should address this issue. In addition, a more detailed analysis of developmental changes in desire for information would be informative. Although we showed no difference between adolescents and preadolescents on total amount of information desired, it is possible that these developmentally distinct groups want different *formats* of information. Future research should also continue to evaluate measures for ascertaining children's desire for information and should follow-up postoperatively to examine whether children feel that they asked for or received the "right" information. Although children reported a strong desire for comprehensive information prior to surgery, we do not know the impact of such information on behavioral outcomes. Thus, future research should examine preoperative information on postoperative recovery. Finally, while we have identified that the vast majority of children desire perioperative information, a minority of children does not prefer to receive comprehensive information and as such tailoring the information to the needs of the child is necessary. Despite limitations, this study has several strengths that add to the literature. Specifically, we recruited a relatively large number of children from two sites in order to increase generalizability of our findings. In addition, because we queried children at the stress-point (i.e., on the day of surgery) we avoided the problems of retrospective reporting.

The findings of this report are particularly important to the practicing anesthesiologist. Not uncommonly, anesthesiologists attend primarily to parents during the preoperative interview while attending significantly less to the child.²⁰ While it is difficult to provide perioperative information within the settings of a busy surgery center, we submit that it is an important function that can be provided by healthcare extenders. Figure 1 lists the 16 items that most children felt they "really have to know" before surgery. Based on the results of this study, these items should be addressed with majority of children in the age group of 7-17 years who express the will to hear about this information. We also suggest that a more child-centered approach to pre-surgical preparation should be implemented.

Implications

Although most preoperative preparation programs are based on provision of information for children, there is little data regarding what children want to know about surgery. Findings of the present investigation suggest that perioperative information should be tailored based on the needs of the child and that the majority of children would like to know all information. Healthcare providers ought to pay particular attention to ensuring children are provided adequate information regarding pain following surgery.

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Pain

- Will the operation hurt?
- Will there be pain? If so how bad will it be?
- How long will I be in pain after the operation?
- Will I feel any pain?
- How is it going to feel?

Eating

- What am I allowed to eat before the operation?
After the operation?
- When will I eat after the operation?

Anesthesia

- Will I wake up in the middle of the surgery?
- When you are asleep will you feel it?
- Will I feel sick or drowsy after the operation?
- Will my Mom and Dad be there when I wake up?

Preoperative and Discharge Procedures

- Will the doctor tell me about the operation and what it will be like when I go home?
- When will I get to go home?
- Will I stay overnight?

Medical Condition

- Will I be alright?
- Can this problem I have come back?

Figure 1. Recommendations of questions that *must* be addressed with children prior to surgery.

Table 1

Baseline Characteristics

	<i>n</i> = 143
<i>Parents</i>	
	Mean ± <i>SD</i>
Trait Anxiety (STAI)	37.5 ± 6.8
State Anxiety - holding area (STAI)	39.6 ± 9.6
<i>Children</i>	
Age (years)	10.7 ± 2.8
Ethnicity	
Caucasian	64%
Hispanic/Latino	6%
African American	6%
Asian American	5%
Bi/multi-racial	4%
Gender (female;male)	52% ; 48%
Type of Surgery	
ENT	40%
General Surgery	30%
Orthopedic	10%
Plastics	6%
Other	15%
Had Previous Surgery	36%
Temperament (EASI)	
Emotionality	10.1 ± 3.6
Activity	14.2 ± 4.1
Sociability	18.3 ± 2.6
Impulsivity	11.2 ± 3.7
Trait Anxiety - (STAIC)	33.0 ± 6.6
State Anxiety - holding area (STAIC)	34.2 ± 8.0

Note.

STAI = State-Trait Anxiety Inventory

EASI = EASI Temperament scale

STAIC = State-Trait Anxiety Inventory for Children

Holding = STAI/C measurement taken in the preoperative holding area

Table 2

CDI Frequencies - "I Really Have to Know"

Percentage Endorsed	Content of Question
22.6%	1. When I am awake will you tell me what happens next the whole time?
36.5%	2. Will the doctor come and see me before the operation?
51.8%	3. Will the doctor tell me about the operation and what it will be like when I go home?
54.0%	4. When will I get to go home?
43.1%	5. What is going to happen?
43.8%	6. What are they going to do?
51.8%	7. What am I allowed to eat before the operation? After the operation?
37.5%	8. What will they do to me?
36.8%	9. Will I get a needle?
38.2%	10. What will happen afterwards?
14.0%	11. Will I lie down?
56.6%	12. When will I eat after the operation?
29.6%	13. When will I go back to school?
39.3%	14. Will I have to come back?
33.3%	15. Will I go back to the hospital?
47.8%	16. How long will I be asleep for?
44.0%	17. How will they put me to sleep?
41.0%	18. How do you get put to sleep?
61.9%	19. Will I wake up in the middle of the surgery?
46.3%	20. How long will the operation take?
40.3%	21. How long will I be in the operating room?
52.3%	22. Will I stay overnight?
42.4%	23. How long will I be in the hospital?
35.1%	24. How long will I be away from school after the operation?
28.2%	25. What does the operating room look like?
26.0%	26. What does the recovery room look like?
24.4%	27. Are you allowed to use game boys?
58.0%	28. Will my Mom and Dad be there when I wake up?
51.1%	29. When you are asleep will you feel it?
63.1%	30. Will the operation hurt?
71.5%	31. Will there be pain? If so how bad will it be?
66.2%	32. Will I feel any pain?
67.7%	33. How long will I be in pain after the operation?
53.1%	34. How is it going to feel?
51.5%	35. Will I feel sick or drowsy after the operation?
57.7%	36. Will I be alright?
53.1%	37. Can this problem I have come back?
40.0%	38. Will I have scars?

Percentage Endorsed	Content of Question
36.9%	39.What will the cut be like?
23.1%	40.Who will mind my pet?

Table 3

Five Most Highly Endorsed Items by Children in Information Desired and Information Avoidance Categories

Percentage Endorsed	I Really Have to Know + I Might Want to Know
91.5%	How long will I be in pain after the operation?
89.3%	Will I feel any pain?
88.4%	Will there be pain? If so, how bad will it be?
87.7%	Will the operation hurt?
86.2%	Will I be alright?
Percentage Endorsed	I Don't Want to Know
19.1%	Will I get a needle?
13.1%	What are they going to do?
12.6%	Will I have to come back?
12.5%	What will they do to me?
12.3%	What will the cut be like?