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# Treating Perioperative Anxiety and Pain in Children: A Tailored and Innovative Approach

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# Abstract

**Summary**—Millions of children undergo outpatient surgery in the United States each year; the overwhelming majority will experience significant perioperative anxiety and pain. Behavioral preparation programs focused on skills acquisition and modeling, considered essential for effective preparation, are no longer offered to most children and families in the outpatient surgery setting. Moreover, what little preparation does occur is typically generic in nature, rather than tailored to unique characteristics of the child and family. Untreated anxiety and pain have significant implications for children's short- and long-term recovery and future interactions in the medical environment. The rapid growth of the World Wide Web and increasing access to Internet by families across the country provides an opportunity to develop tailored, Web-based behavioral preparation programs that can be accessed repeatedly at times convenient to the child and family, that include coping skills training and modeling, and that can provide unique output based upon child and parent characteristics known to impact perioperative pain and anxiety. In this review article we present a conceptual framework for a computer-based intervention that may transform the way we manage children and parents before and after surgery.

# Keywords

Anxiety; outpatient surgery; patient-centered care; coping behavior; internet; pediatric psychology

# The Challenge: Preoperative Anxiety

Every year many millions of children undergo anesthesia and surgery around the world. On the day of surgery, children and parents typically wait in a preoperative holding area and during this time period, children are fearful about the impending surgery, specifically around the anticipated separation from their parents and pain <sup>1,2</sup>. Indeed, Kain et al reported that up to 60% of all young children undergoing anesthesia and surgery report significant anxiety<sup>1,2</sup>. The anxiety felt in the preoperative holding area is increased once children enter the

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operating room, where monitors are applied, a mask is held over the child's face, and volatile anesthetics are administered. Occasionally the stress and fear are such that children wet themselves, and may attempt to escape from the healthcare providers <sup>1,3,4</sup>. Indeed, up to 25% of young children who have not received sedative premedication or parental presence need to be forcefully held down during the induction of anesthesia <sup>3</sup>.

In terms of the impact of preoperative anxiety, children who are highly anxious before surgery have been found to have a significantly higher postoperative pain, delayed hospital discharge, and higher incidence of emergence delirium, sleep disturbances, and other maladaptive behavioral changes that last up to a few weeks following surgery <sup>5,6</sup>. Indeed, although emergence from anesthesia is uneventful for most children, about 12-18% of children develop emergence delirium (ED) <sup>6</sup>. Although the etiology of emergence delirium is unclear it is likely related to specific drugs, pain, anxiety, and the temperament of the child <sup>7</sup>. In fact, it is reported that child behavior during induction predicts the occurrence of ED <sup>3 8</sup>. Studies from 40 years ago found that *inpatient* surgical experience could result in behavioral problems <sup>9-11</sup>. Investigations that repeated earlier studies determined that up to 40% of children undergoing outpatient surgery still exhibit new onset maladaptive behavioral responses (e.g., nightmares and separation anxiety) at 1-2 weeks after surgery <sup>1,5,12-14</sup>. Both the anxiety of the child and mother have been associated with the presence of postoperative maladaptive behavioral changes<sup>1,15</sup>.

Anxiety before surgery is inclusive to both children and their parents <sup>1,16-20</sup>. Parental anxiety is important not only because it causes hardship to the parents but also because it is strongly related to child preoperative anxiety and postoperative pain <sup>1,21</sup>. High parental anxiety is also related to the development of postoperative maladaptive behavior changes in children following surgery <sup>1</sup>. Reducing parental anxiety has been shown to decrease preoperative anxiety in children <sup>22</sup> and most parents who participate in preoperative preparation programs display reduced anxiety on the day of surgery <sup>1,16,17,23-27</sup>. Unfortunately, a recent survey study shows that at the current time the overwhelming majority of families in the United States (U.S.) receive no treatment for preoperative anxiety <sup>28</sup>.

## The Challenge: Postoperative Pain

Of the millions children who undergo surgery every year, the majority will experience significant pain in the hospital <sup>29</sup>. At home, a similar picture emerges where most children are in pain while recovering at home immediately after surgery, and approximately one-third of children report significant pain that continues up to one week after surgery <sup>13,14</sup>. Unfortunately, healthcare professionals underestimate postoperative pain in children <sup>30</sup>. In 1983, Mather and Mackie reported that 31% of pediatric surgical patients were not given postoperative analgesics <sup>31</sup>. Amazingly, 13-years later, the same rate of under treatment of postoperative pain was reported, <sup>32,33</sup> with a 2002 investigation finding that 51% of children continued to receive insufficient analgesics after surgery<sup>34</sup>. The under treatment of pain in the postoperative setting is particularly problematic given the impact of children 's early pain experiences. For instance, significant medical procedure distress in children has been linked years later to adults' reports of pain and anxiety regarding medical events <sup>35</sup>. In addition,

early painful procedures have been associated with changes in sensitivity to later medical procedures <sup>36</sup>. Recent findings have even demonstrated alterations in pain neuropathways as a result activation of the nociceptive system early in development <sup>37</sup>. In addition to under treatment of pain in the hospital, children are also at risk of under medication at home by parents <sup>38,39</sup>.

Given that the overwhelming majority of children's surgery is now outpatient, parents at home now manage most postoperative pain. This is concerning as parents often under medicate their children's pain, with up to 60% of parents administering less than the prescribed dose of analgesia following day surgery discharge <sup>38,39</sup>. Although explanations for the suboptimal pain management provided by parents at home are not entirely clear, a recent study identified specific parental attitudes toward analgesia that impact medication administration after surgery<sup>40</sup>.

# Perioperative Pain and Anxiety: Current Status

Modalities such as preoperative sedatives, parental presence during induction of anesthesia (PPIA), postoperative analgesics and behavioral preoperative preparation programs are available at the current time to help children to cope with perioperative pain and anxiety. Currently, only a minority of children receives a preoperative sedative to manage this anxiety, and an additional minority of children are accompanied to the operating room by their parents <sup>41</sup>. A national survey conducted by our laboratory of more than 4000 anesthesiologists found that most young children in the U.S. are taken into the operating room alone without the use of either premedication or parents in the operating rooms  $4^{1}$ . Reasons for this under treatment include cost-containment efforts and lack of understanding of the adverse sequelae of perioperative anxiety and pain as well as lack of evidence to the effectiveness of modalities such as behavioral preparation programs. Unlike sedatives, for example, the effectiveness of PPIA to reduce preoperative anxiety remains unproven when parents are not provided with education on their role and behavior in the operating room 42-47. The use of behavioral preparation programs for surgery, which were once very popular, has decreased significantly in U.S. A random survey of 59 hospitals in the U.S. found that over 90% of community hospitals had no surgical preparation programs and no child-life programs. In addition, even though 70% of childrens hospitals provided surgical preparation in the form of child life services for children undergoing inpatient surgery, just 20% of preparation programs occurred before the day of surgery. Outpatient preparation programs were characterized by very low participation rates (17-32%), due in part to the fact that about 80% of hospitals require a providers' referral for participation and were available primarily for children with special needs. <sup>28,48</sup> [Kain et al. Anesthesiology 2006]. The fact that 80% of hospitals surveyed offer a shortened program delivered on the day of surgery just before the procedure is likely a result of the shift toward outpatient surgery and costcontainment efforts that discourage time-intensive behavioral interventions in hospitals. Unfortunately, a recent video-capture study found that anesthesiologists, surgeons, and nurses each spend less than 6 minutes on the day of surgery with outpatient children <sup>49</sup>. Clearly, the rationale that day of surgery preparation can replace the traditional preparation programs that are conducted several days prior to the procedure is simply not valid. Finally, current preoperative preparation programs lack of information and training for parents in

pain management, and parental patterns of insufficient analgesic administration.

Furthermore, although behavioral interventions are important in the optimal management of postoperative pain, these interventions work best when children have had the opportunity to practice and build mastery in their use. Given that most surgeries today are conducted on an outpatient basis and little preparation is offered <sup>50</sup>, children's opportunities to learn and practice these pain reduction behavioral techniques are limited at the current time.

We conclude that a new conceptual framework is needed in order to adequately treat the phenomena of perioperative anxiety and pain. This framework should take into account that futurists predict that by 2015 about 90% of all pediatric surgery in the U.S. will be performed on an outpatient basis and as well as developments in technology and behavioral sciences.

# Perioperative Pain and Anxiety: Preoperative Preparation Programs

#### **Design Considerations**

Most of the current preoperative preparation literature is dated in the late 1980's and minimal innovation has occurred in this area over the past two decades. For example, preoperative preparation articles published in the anesthesia, surgery, and nursing literature since 2000 examine programs consisting of written information and modeling. These preparation concepts date back to the 1980's, yet they are presented as "state of the artrr" <sup>51-57</sup>. An editorial by Koinig deplored the expense of hospital-based preparation programs. The solution, he wrote, would be adapting "alternative methods" such as "written information leaflets" <sup>52</sup>, despite the 1997 article that rated written information as the least effective form of preoperative preparation <sup>58</sup>. A recent preparation program indicated the success of a strategy that included support by a psychologist throughout the surgical episode<sup>59</sup>. Clearly such a strategy is not viable in current real world healthcare settings. Other limitations of current preoperative preparation programs include:

- Because these programs are physically located in hospitals, there is a high operational cost associated with them <u>and</u> parents need to take time off work to attend.
- Most of these programs are generic in nature and conducted in groups and thus do not address variations across individuals.
- Most preparation programs do not use maximally effective techniques such as enhanced coping skills because of their high expense. Rather, many resort to lowcost group lectures, written material, and operating room tours.
- Most preparation programs prepare the child and parent for the "overall" perioperative process, not for specific components such as postoperative pain <sup>28</sup>
- Hospital-based preparation program are accessible only at one time point.
- Most current preparation programs are not geared toward parents and do not provide enough perioperative information.

Considering the above limitation of current preoperative preparation programs we submit that future programs should include the following characteristics:

- A future preoperative preparation program must be accessible. Access to the Internet has significantly increased all the around the world. The most recent Pew Internet survey conducted in 2014<sup>60</sup> showed that well over 90% of adults aged 18-49 years are Internet users. Moreover, a majority (80%) of adults who use the internet search for health topics and most households are able to access broadband Internet.
- Surgical preparation programs need to be tailored based upon individual characteristics of children and parents. Tailored interventions are adapted to a specific individual's situation, needs, and/or characteristics <sup>61-67</sup> and are therefore more complex than generic interventions. Tailoring of computer-based interventions is a technique that has become increasingly popular in healthcare <sup>63,64,67-69</sup>. Computer tailoring can efficiently convey information to target medical topics including smoking <sup>62</sup>, cancer screening <sup>70</sup>, and nutrition <sup>62,64,71,72</sup>.
- Preparation for surgery for children and parents should be inexpensive and low in costs. That is, hospitals should have low operational costs associated with the program personnel, and parents should be able to access the preparation program during evening and weekends and not miss time at work.
- The content of future preoperative preparation program should be evidence based rather than motivated by cost and individual biases. An early report suggested that the most effective components of surgical preparation were coping skills training and modeling (observation of targeted skills) <sup>58</sup>. As this opinion is strongly supported by recent literature, coping skills and modeling should be the major components of any future preparation program for children and parents. In addition, key information that parents want to be given before the day of surgery should be included <sup>73</sup>.
- A future program should also be very much focused on pain management given that most parents under treat the pain of their children in the home setting. As the majority of surgery currently is conducted on an outpatient basis, this is of very high importance. Indeed a recent study found parent misconceptions regarding analgesic use for children to be prevalent, including fears of medication side effects, concerns that analgesic use would lead to addiction, and beliefs that analgesia works better when administered less frequently <sup>40</sup>. These beliefs have been linked to the under treatment of children's postoperative pain by parents<sup>74</sup>.

#### **Structural Approach**

We conclude that dramatic increase in access to the World Wide Web opens an alternative avenue for providing surgical preparation to children and families by developing an Internetbased intervention that families can access in the comfort of their own homes, multiple times prior to and after surgery, and that will integrate evidence-based treatments for improving postoperative pain management and reducing preoperative anxiety. Further, the Internet

allows such an intervention to be tailored to empirically chosen characteristics of the child, parent and the surgical procedure. As we indicated above, a computer-based tailored intervention may represent an ideal approach to management of preoperative anxiety and postoperative pain for children undergoing surgery. Various experts define tailoring in different ways. For example, one of the early pioneers in this area, Kreuter and Skinner, defined tailoring "as any combination of information or change strategies intended to reach one specific person, based on the characteristics that are unique to that person, related to the outcome of interest, and have been derived from an individual assessment" 75. We further submit that a tailored intervention has to be developed while taking into account identification of specific barriers (e.g. why do individual parents under treat the pain of their child) and take action to overcome these barriers. Although tailored interventions can be incorporated into printed material, in more recent years the term "computer-tailoring" has vastly evolved. This new methodology is based on real-time assessment of patient input and selection of output content using data-driven decision rules (matrix). In this model, the tailored intervention is based upon three components, an intake (assessing the characteristics, needs and preference of the patient), a matrix (a rule-based decision support system that is based on the intake) and an output (which is directed at affecting the outcome of interest). With this conceptual framework in mind, we will develop for the reader the elements of a futuristic web based preoperative preparation program for children and their parents:

#### The Intake Component of Computer-Tailored Preoperative Preparation

As stated earlier, an initial step in designing and testing a tailored intervention is selecting individual characteristics on which the output component of the intervention will be tailored <sup>76</sup>. Overall, it is well established that child variables (developmental abilities, temperament, coping style), family variables (parental trait anxiety, coping style, attitude toward pain), and the surgical procedure will affect the recovery of a child after surgery and thus should be taken into account when designing a particular preoperative precreation program<sup>77</sup>. As such, each of these variables needs to be examined:

- <u>Developmental abilities</u> change dramatically as the child matures and there is very little in common between the 2-year old child and the 13-year old adolescent. As such we recommend as a first step to target the intervention toward a particular age group. Whereas conceptually, developmental ability of the child can affect the matrix and thus the output of a computer-based tailored intervention, in reality, the wide variation in developmental abilities will necessitate such a highly complex output that it would be prohibitive to develop. If a certain age group is to be chosen, we propose that an initial computer-based tailored intervention focus on younger children (2-5 years old) given it is well established they are significantly more vulnerable to anxiety during the perioperative period.
- <u>Child temperament</u> is important to factor into a preoperative preparation program<sup>2</sup>. Specifically, children high in negative emotionality show more anxiety on the day of surgery. It is notable that while the construct of negative emotionality includes several temperamental variables including anger, sadness, and fearfulness; fearfulness is the most relevant temperament marker for tailoring in the

preoperative setting. Fearful temperament generally refers to the degree to which children respond with worry or unease to potentially threatening situations <sup>78</sup>. Thus, children who are high in temperamental fearfulness are more likely to react with anxiety to the potentially threatening surgical environment and will benefit from thorough anxiety management interventions such as coping skills training and exposure <sup>79</sup>. Moreover, fearful temperament may affect the outcomes of the intervention. For example, Kochanska and colleagues <sup>80</sup> demonstrated that the efficacy of parenting styles differed based on children's fearful temperament. Children who are highly fearful are most likely to comply with directions and internalize parental messages when parents use "gentle, low power discipline" 80. In children with low fear however, this type of discipline is not effective as it does not generate enough anxiety in the child to facilitate compliance. High power discipline is also not effective for these children, as it may lead to anger rather than compliance. Instead of discipline techniques for low fearful children, Kochanska proposes capitalizing on positive emotions to generate compliance and internalization of parental messages.

- Parental trait anxiety is a good predictor of parental state anxiety on the day of surgery <sup>81</sup>. Further, data from our group suggest that parents who are high in anxiety respond differently to perioperative interventions than their low anxiety counterparts <sup>82</sup>, specifically, those parents who are high in anxiety tend to respond less favorably to traditional preparation programs than those who are low in anxiety. This may be because most of the existing preparation programs provide information to parents about the process on the day of surgery, but do not teach specific skills for parents to manage their own anxiety. Given there are data within the procedural literature to suggest that teaching parents coping skills can decrease their own anxiety, these skills should be imparted to high anxiety parents in this program.
- Parental coping will affect how they respond to preoperative preparation programs and this characteristic has been generally defined as volitional strategies used by individuals to modulate reactions in response to stress <sup>83</sup>. Coping literature has differentiated between strategy and style models of coping that are somewhat akin to state and trait conceptualizations. Coping strategy (state) conceptualizations focus on specific techniques that individuals use to modulate stress (e.g., seeking out information) whereas coping style (trait) conceptualizations focus on the patterns by which individuals respond to stress. One coping style model that is particularly relevant to the current application is the Monitor/Blunter framework proposed by Miller and colleagues <sup>84</sup>. This framework categorizes coping styles based on the degree to which individuals seek out and attend to health-related information and how they respond to this information. Individuals in the "monitor" category scan medical information for threatening cues <sup>85</sup> and respond with greater anxiety to health risks 86. Despite their anxious reactions, monitors desire and respond best to comprehensive information, particularly information that outlines means by which to reduce health risks <sup>87</sup>. In contrast to "monitors", "blunters" become distressed at detailed health-related information and may distract

themselves as a means of avoiding this information <sup>84</sup>. Therefore, efficient and direct information focused on benefits is preferable <sup>87</sup>. Several studies have examined interventions tailored based on this monitor-blunter framework and have consistently shown that coping style-matched interventions are more effective than mismatched interventions <sup>87-89</sup>.

- <u>Parental pain management attitudes</u> have been associated with how well parents managed their children's pain <sup>40</sup>. For example, parents endorsed beliefs that using pain medication in childhood may lead to later drug abuse and that pain medication works best when used as little as possible. Education regarding pain management has been found to increase favorable attitudes in nurses <sup>90</sup> and videotaped interventions have been found to alter parents' pain knowledge <sup>91</sup>. Research on attitude change indicates that interventions targeted to specific attitudes are more effective than those that are presented in a more general way.
- In addition to personality and attitude variables, it will be important for such a tailored intervention to include information on parental preferences for perioperative interventions. In particular, these include use of sedative premedication (e.g., midazolam) and parental presence at anesthesia induction (PPIA) <sup>92</sup>. With regard to PPIA, parents may want to accompany their child to the operating room and parents who are prepared to enter the operating room are more effective at managing their children's anxiety than those who are not prepared <sup>93</sup>. Thus, such preparation will be provided as part of a newly developed intervention.
- <u>Different types of surgery</u> will result in different perioperative experiences, especially in regard to the quality and intensity of postoperative pain. For example, tonsillectomy commonly results in significant pain in the recovery room and at home <sup>94</sup> whereas pain typically resolves quickly for procedures such as pressure equalizing tubes as well as inguinal hernia repair. Providing accurate expectations for postoperative recovery is important, particularly sensory aspects (i.e., pain) associated with the procedure <sup>95</sup>.

#### The Matrix and Output Components of Computer-Tailored Preoperative Preparation

The decision process of a computer-based tailored intervention is based on real-time decision support and takes into account all the information that has been provided by the parent and child in the intake component. The output of such a program should be evidence based and could sequentially address each of the five temporal divisions of surgery: 1) Home prior to surgery; 2) Holding area; 3) Anesthesia induction and surgery; 4) Recovery room; and 5) Home following surgery. Each of these output modules should be included for both parents and children. The child component should make use of three strategies: information provision, modeling, and coping skills training that have been previously reported as ideal for preparing children for surgery. The child component should be ideally age-appropriate, animated, engaging, and accessible to 2 to 5 year old children. The parent component should include two concepts: information and coping skills education and practice. Use of multiple media formats (e.g., audio and visual) to provide parental information will increase engagement in the program. We recommend that in such a program parents and children will work together to complete the child component, ensuring

that parents also learn children's skills. In addition, "parent teaching" time should be built into the program.

Ideally, such a preparation program will provide information about the child and parent to anesthesiologists and nurses before the day of surgery. While completing the intake portion of the program, parents could be asked for personal information about their child (What is the child's favorite cartoon character, what is the child's favorite pastime). This information will then be shared with the clinician on the day before surgery. Clinicians will be able to use this information to quickly build rapport with the child on the day of surgery and may also be able to use this information to aid in distraction during anesthesia induction. Also, the clinicians should be informed of parents' preferred coping styles (monitor or blunter), anxiety level (high or low), and children's temperament (fearful or non-fearful). Accompanying these summaries should be tips for clinicians to tailor their day of surgery behavior to parents' and children's characteristics. For example, clinicians will be provided with instructions on how to interact with "monitor" parents such as "This parent will respond well to detailed information on the process of surgery. They will appreciate a thorough discussion of the risks and benefits of the procedure and reassurance about measures taken to reduce risks. This parent will also benefit from a thorough discussion of expectations for the postoperative course of recovery."

#### **Technical Considerations**

No discussion on an ideal computer based tailored intervention directed at preparing the child and parent for surgery would be complete without a discussion of some of the technical aspects. Ideally, for the age group involved, an animation company with significant web design abilities should be chosen. Custom characters designed for this program will be stewards through the virtual experience. The main character who will navigate the child through the intervention should be neutral in gender, age, and ethnicity so that any child can relate to and bond with it as a new friend. The intervention should teach the child about the perioperative process so he or she knows what to expect, understand the roles of the health care providers who will be involved in the surgical process, and learns strategies to manage anxiety. Presenting clear information in a fun way will keep the child engaged to maximize the effectiveness of content. Security consideration should include a Secure Socket Layer (SSL) certificate allowing for 128bit encryption between client and server transactions. Participants can be assigned user names that will not be associated with their real names. All data can be stored and accessed in accordance with HCFA's Security Policy and the Health Insurance Portability and Accountability Act (HIPPA). Multiple, redundant layers of firewall system will also protect secure data. Risk minimization strategies summarized by NIMH (Internet based Research Intervention Chart, October 2003) should be implemented.

## Conclusion

The Internet and the World Wide Web are markedly changing our society and we suggest that the future of treating perioperative anxiety in pain in children capitalize on this medium to transform the way we manage children and parents before and after surgery. In this article

we presented a conceptual framework for a computer-based intervention that is aimed to treat perioperative anxiety and pain in children. Our research center has been funded by the National Institute of Health to develop such an intervention (WebTIPS) and are in the process of providing data to support its efficacy with hopes to disseminate such a program to hospitals across the country.

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