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## Family-centered Pediatric Perioperative Care

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**F**AMILY-CENTERED care is an approach to the planning and delivery of health care that is based on partnerships among patients, families, healthcare providers, and hospitals. Family-centered care encourages a collaborative, team approach that respects individual and family strengths, cultures, traditions, and expertise.<sup>1</sup> Providing care in a family-centered way honors the involvement of the patient, family, and informal caregivers and improves outcomes by encouraging communication among all stakeholders, enhancing coordination and promoting integration of medical care.

Despite the attention to family-centered care in specialties such as pediatrics,<sup>2</sup> neonatology,<sup>3</sup> and emergency medicine,<sup>1</sup> there has been very little integrated literature on this unique approach to patient care in anesthesiology. Although there are studies within the field that may fall into the general rubric of family-centered care, guidelines and policy statements have not been developed. Thus, the purpose of this Clinical Concept and Commentary article is to promote the philosophy of family-centered care in anesthesiology by providing a practical and clinically relevant model of delivering pediatric perioperative care in a family-centered manner. The basic message is that families are an integral part of the perioperative care team and should be treated as such. Efforts

should be made to establish collaborations by openly communicating, developing a shared vision for the care of the child, and building a cohesive care team that includes healthcare providers and family members throughout the perioperative period.

### Family-centered Pediatric Perioperative Care

Figure 1 is a proposed model of family-centered pediatric perioperative care. This model highlights important components of care in the preoperative period (preparation for surgery), in the intraoperative period (management strategies), and in the postoperative period (pain management and recovery at home). In addition to noting components of care, this model also identifies potential family and healthcare provider or system variables that can affect the way in which family-centered care is delivered. The factors such as parents' and children's anxiety, family history with medical procedures, and parents' and children's coping styles and preferred coping strategies should be taken into account when delivering family-centered care. Provider characteristics such as training in working with children and families, and communication and interaction style will also affect how well these strategies can be implemented, as will systemic factors such as organizational policies and administrative support for family-centered care. These moderating factors are examples rather than an exhaustive list, and we expect that further attention to family-centered care in anesthesia will identify more of these factors.

### Preoperative Period: Family-centered Preparation

The first step in providing family-centered pediatric perioperative care occurs before the day of surgery. There is a long history of interest in preparing children for surgery. Indeed, preoperative preparation programs have been in existence since the early 1960s, and more than 100 articles have been published evaluating such programs. On the surface, preparation seems to be a simple concept: tell children what is going to happen, and their anxiety will decrease. In reality, however, preparation is not so simple. Research has revealed that there are many intricacies of preparation: what informa-

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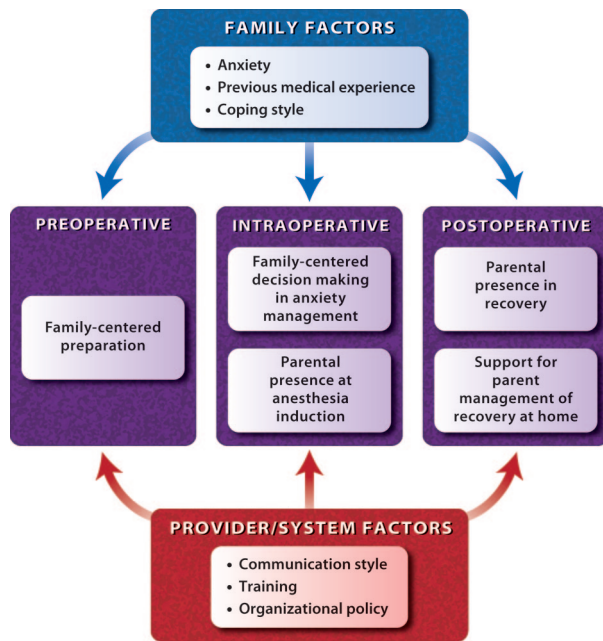


Fig. 1. Model of family-centered pediatric perioperative care.

tion is provided, when and how it is provided, and by whom are all key factors considered. For those readers interested in a more detailed summary literature on preparing children for procedures, Jaaniste *et al.*<sup>4</sup> provide a review of preparation for children. In terms of the content of information, there is clear evidence that children benefit from both procedural and sensory information. That is, children should be told about what will be done during the procedure and what the child may experience. Information should be provided in a developmentally appropriate, nonemotional manner and should be sufficiently detailed to allow the child to develop realistic expectations of the procedure. Information about pain should not be withheld. In fact, a recent survey of children undergoing surgery indicated that children want comprehensive information about their procedure, especially with respect to pain.<sup>5</sup> In addition to information on the procedure itself, children (particularly those with negative medical experiences) should be provided with training in coping skills such as distraction and deep breathing. In terms of how to deliver information, written material alone is not effective, nor is medical play using dolls. Modeling of desired behaviors by a peer (*via* videotape) is particularly effective and supported by evidence.<sup>4</sup>

Although preparation of children is undoubtedly important, family-centered preparation goes beyond just the child. There is strong evidence that parent's anxiety on the day of surgery is highly associated with child's anxiety<sup>6</sup>; thus, parents should also be active targets of family-centered preparation. Similar to children, parents desire information about their child's procedure. In fact, more than 50% of parents do not just want to know, but believe that they have a right to know about all possible complications, details on pain or pain relief, and details on sedative premedication.<sup>7,8</sup> Indeed, when provided detailed information, parents were not more

anxious when compared with parents who received minimal information.<sup>7</sup> In a systematic review of literature on communicating with parents about their children's anesthesia, Frank and Spencer<sup>9</sup> noted that (although there is a need for further research) information provided to parents can increase knowledge and decrease parent's anxiety.

The ADVANCE (anxiety reduction, distraction, video modeling and education, adding parents, no excessive reassurance, coaching, and exposure/shaping) program is an example of an effective family-centered intervention that integrates parent and child preparation.<sup>10</sup> ADVANCE is a multimodal intervention providing procedural and sensory information for parents and children, training in coping skills for children and parents, and a parent-implemented graded exposure plan for children. The intervention was delivered *via* written and audiovisual (video) materials and included coaching by research assistants. The tenets of family-centered care were integral in this intervention in that it included parents and children from the outset, respected parents' role in the provision of children's care, and built on parents' and children's unique experiences with medical procedures. The results of a large-scale randomized control trial evaluating this intervention indicated that families participating in the intervention displayed lower preoperative anxiety (both child and parent) and better child postoperative outcomes (*i.e.*, emergence delirium, need for analgesics, and time to discharge).<sup>10</sup> Further details on the components of the ADVANCE intervention are found in the appendix of the original study.<sup>10</sup>

### Intraoperative Period: Family-centered Decision Making

A central tenet of family-centered care is the facilitation of collaboration between families and healthcare professionals. Families' diversity in values, preferences, and experiences should be recognized when considering options to manage children's preoperative anxiety and postoperative pain. The two major interventions that may be used to manage preoperative anxiety in children are sedative premedication and parental presence at anesthesia induction. Providing care in a family-centered way implies that the decision on which (if either) of these interventions to use should be collaboratively made between anesthesiologists and families. Unfortunately, at this point, there is little empirical literature to guide how to engage in this decision making. We do know that parents have preferences about interventions used to manage their children's anxiety. In a study of parents of children who were treated with either premedication or had parental presence at a previous surgery, a significant majority of parents indicated a desire to be present at induction<sup>11</sup>; only 23% of parents whose children had been premedicated chose this intervention again. We also know, however, that parents are not always good at predicting anxiety. Indeed, in one study, it was found that mothers were not as good as attending anesthesiologists in predicting children's anxiety at anesthesia in-

duction (although fathers were better predictors than mothers).<sup>12,13</sup> We also know that mothers who have a stronger desire to be present during anesthesia induction tend to report higher anxiety and have children who are more anxious at anesthesia induction.<sup>14</sup> Thus, it is clear that decisions on preoperative anxiety management should be a collaborative process between parents and anesthesiologists. Anesthesiologists may make a recommendation about the type of intervention but only after providing information and carefully soliciting questions about all therapeutic options. Parents should be asked about their child's experience with previous surgeries, particularly with any interventions for preoperative anxiety.

Although attention has been paid to parents in the process of decision making, children have been largely ignored in the empirical literature; thus, clinical recommendations are difficult to make. In terms of including children in the perioperative process, it is notable that most of the communication on the day of surgery by healthcare providers is directed to parents and not to children.<sup>15</sup> We are only aware of one study that specifically examined children as part of the decision-making process. Proczkowska-Bjorklund *et al.*<sup>16</sup> found that when children were provided with less information and were engaged in more bargaining, children were more likely to refuse to take premedication. Future research and clinical attention should be devoted to understand the role of the child in the perioperative process, particularly with respect to decision making.

### **Intraoperative Period: Parental Presence at Anesthesia Induction**

Parental presence at anesthesia induction supports family-centered care by allowing parents to be involved in caretaking of children and is consistent with recommendations in other areas of medicine such as parental presence for procedures in the emergency department.<sup>1</sup> Parental presence is a common intervention offered for children's preoperative anxiety. Indeed, more than 40% of hospitals in the United States have some policy allowing or encouraging parents to be present,<sup>17</sup> and it is likely that there are more clinicians who use parental presence without a formal policy. Parental presence has the benefits of decreasing separation anxiety by not requiring the child to separate from the parent and has the additional benefit of decreasing the need for premedication, thus preventing potential side effects and increased monitoring required for pharmacologic anxiolysis. Parental presence is overwhelmingly preferred by parents and increases parental satisfaction, thus improving public relations of hospitals.<sup>11</sup> Indeed, some would argue that being present at anesthesia induction is a basic right of parents. Parental presence does have its drawbacks, however. In our research and clinical work, we have heard concerns with the routine in the operating room (*i.e.*, a need for staff support for parents and escorting parents to the operating rooms) and stress on the providers in the operating room. Concerns have also been

expressed regarding parents' responses to being in the operating room. Although data suggest that parents do not have significant maladaptive physiologic responses,<sup>18</sup> there is still concern for the psychological effects of parents on seeing their child once anesthesia is induced or with parents being present during a particularly difficult induction. Indeed, there are legal implications if a parent who is invited into the operating room by a medical staff member faints and is injured.<sup>19</sup> Unfortunately, there is no validated measure to identify which parents are at risk for experiencing adverse events. Currently, we rely on anesthesiologist's judgment and, although surely accurate at times (especially in the case of experienced anesthesiologists), do not know the validity of our judgments. Although erring on the side of caution is prudent, we are likely missing out on opportunities to support parents' roles in caring for their child and facilitating easier inductions.

A single issue underlying the debate on parental presence is the questionable evidence of its efficacy. A recent review of 14 studies of parental presence at anesthesia induction<sup>20</sup> concluded that parental presence did not decrease children's anxiety when compared with no parental presence. Although there are no data to suggest that this practice is harmful, it does not seem to be particularly helpful either. The lack of efficacy data has been cited as a reason for not incorporating parental presence into a standard practice.<sup>21</sup> We believe that focus on efficacy data from randomized controlled trials has led the debate over parental presence awry. The issue is not whether a child is better off if their parent is randomly assigned to be present at anesthesia induction; indeed, this question has little to do with family-centered care. Family-centered care is not about providing care in the same way to every family (*i.e.*, encouraging all parents to be present). Instead, it is about respecting the role of family, encouraging collaboration, and honoring individual differences among families. Some parents come with the skills and experience to be an effective member of the induction team, whereas others may wish to be present but are in need of support or preparation to be effective in this role. The importance of preparing parents to be present at induction should not be underestimated in these cases. Another group of parents may not want to be present but may need validation that this choice does not reflect poorly on them as a parent. Our task is to work with families to identify where they fall on this continuum and to provide care that is consistent with these perspectives. To further this agenda, future work will need to address what parents actually do when they are present and ways to facilitate effective behaviors of parents at anesthesia induction.

### **Postoperative Period: Parental Presence in the Recovery Room**

In contrast to the debate about parental presence at anesthesia induction, most hospitals allow parents in the recovery room after their children's surgeries. To date, there is only

one randomized controlled trial of this practice.<sup>22</sup> From our perspective, the view of parental presence in the recovery room as a standard practice is encouraging for family-centered care, but this should not mean research should stop on how to make this practice most effective. In other procedural pain contexts, we know that parents' use of distraction and instructions on coping skills (*e.g.*, deep breathing) are associated with less distress, whereas use of reassurance and empathy are related to more distress in children.<sup>23</sup> To facilitate true family-centered care in the recovery room, parents should be provided with information on expectations of their role (*e.g.*, when or how can they touch their child and how to alert a nurse if they think their child has pain) in addition to instructions on ways to help their children cope (*e.g.*, distraction and holding the child's hand).

### Postoperative Period: Support for Parent Management of Recovery at Home

The rise in outpatient surgeries for children has left parents to manage children's recovery at home, particularly with regard to postoperative pain; thus, family-centered care is integral in the postoperative period. Unfortunately, data suggest that children's pain management and recovery at home is less than optimal.<sup>24</sup> Parents and children may have misconceptions about pain medication,<sup>25,26</sup> and parents often do not provide recommended doses of pain medication at home.<sup>27</sup> Side effects of pain medications and children's refusal to take medications also likely play a part in parents' decisions on whether or not to provide medication to their children. Although nonpharmacologic methods of pain management may also be helpful in managing postoperative pain, parents often use these strategies only in a limited manner.<sup>28</sup>

We must recognize that parents are not medical professionals and often do not have experience in providing medical care for their children at home. Parents are often provided with information on pain management and how to care for their child at home at the time of discharge or in the recovery room when they are already anxious and in a time of stress. In a study of discharge information provided to parents of children undergoing surgery, parents reported that information was generally sufficient but the timing, content, and method of provision could be improved.<sup>29</sup> Parents' ratings of insufficiency of information in this study were related to higher children's pain after surgery.

Although information provision is a necessary step, we must recognize that family-centered care is not just providing information in a one-way manner at discharge. Understanding families' experiences with pain management and healthcare and their perspectives on pain medication and impressions of nonpharmacologic interventions are all key components of delivering care in a family-centered way and of ensuring optimal postoperative management. Although in some cases, anesthesiologists may not be primarily responsible for discussing discharge plans, they should take an active role in communicating with families about pain manage-

**Table 1. Elements of Perioperative Family-centered Care**

Recognize that the family is the constant in the child's life, whereas the perioperative personnel are variable.
Facilitate parent and professional collaboration at all levels of health care including care of an individual child, program development and evaluation, and policy formation. Parental presence in the operating rooms and recovery area are good examples.
Recognize family strengths and individuality. Respect different methods of coping.
Assure that the design of health care perioperative delivery systems is flexible, accessible, and responsive to families.
Share complete and unbiased information with parents about the surgical procedure and their child's condition on an ongoing basis.
Understand and incorporate the developmental needs of children and families into perioperative health care delivery systems and preparation for surgery.

ment as there is no need to avoid repetition; families will benefit from reiteration of recommendations from multiple providers.

### Conclusions, Practice Implications, and Future Directions

To ensure that family-centered care becomes a standard of practice, there is a need for commitment at both the individual and the system level. Providing family-centered care should not be an expensive or time-consuming endeavor. Yes, many preparation programs currently require additional staff or resources. There is a need to address this issue by developing time and cost-effective ways of providing preoperative preparation using innovative delivery strategies (including the Internet or telehealth). In the meantime, every practitioner can strive to restructure the time they already spend with patients to involve families in collaborative decision making and to solicit parents' and children's perspectives and concerns about managing recovery at home. Table 1 presents important individual and systemic components of family-centered care. There is a need for organizational policies that support family-centered care with built-in flexibility for including children and parents in the perioperative process. There is also a need for healthcare provider and team commitment to provide family-centered care. Peers who practice together can influence each other and can provide support and consultation on challenges that may arise in the implementation of this practice. Many anesthesiologists are already skilled in providing family-centered care and should become champions for this practice. Finally, there is a need to develop standards for incorporating family-centered care

into training. Education and experience in the skills required to incorporate families into care should be a standard part of residency and fellowship programs to ensure that the next generation of practitioners considers family-centered care as a standard care.

Family-centered care is a philosophy that has been embraced throughout pediatric care. Standard practice guidelines for family-centered care have not yet been developed for pediatric anesthesiology, but this philosophy has clear implications for perioperative care. Delivering care in a family-centered manner will improve both patient and system outcomes and requires an ongoing commitment in anesthesiology research and practice.

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