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# When Parents Have Misunderstandings About the Risks and Benefits of Palliative Surgery

Berklee Robins, MD, MA,<sup>a</sup> Adam Booser, MD,<sup>b</sup> John D. Lantos, MD<sup>c</sup>

When a child needs surgery, both the surgeon and the anesthesiologist must obtain informed consent from the parents. In theory, each specialist obtains permission for their respective portion of the procedure, with the anesthesiologist only obtaining informed consent for the administration of anesthesia and management in the operating room and recovery room. However, he or she may occasionally realize that the parents have misunderstandings about what the surgery and perioperative course entail. In such cases, he or she must decide whether their role is only to discuss the issues related to anesthesia care or whether he or she should also clarify the range of expected outcomes and the postoperative course after surgery. We present a case in which such a dilemma arose and on which we sought experts in anesthesia and ethics to comment.

## abstract

When a child needs surgery, both the surgeon and the anesthesiologist must obtain informed consent from the parents. Usually, this does not lead to conflicts. The surgeon explains the goals of surgery and the associated risks and benefits. The anesthesiologist explains the risks of anesthesia. However, sometimes, especially when surgery is palliative rather than curative, parents may not fully appreciate the implications of undertaking a surgical procedure in relation to their ultimate goals of care. This may come to the attention of the anesthesiologist. The anesthesiologist then faces a dilemma: is his or her job only to explain the risks of anesthesia? Or does he or she have a larger responsibility to make sure that the parents truly understand the nature of surgery and the postoperative course? We present a case in which these dilemmas are raised and on which we ask experts to comment.

### CASE PRESENTATION

“Susana” had a prenatal diagnosis of severe brain and

craniofacial malformations (lobar holoprosencephaly). During the pregnancy, her parents consulted with multiple pediatric subspecialists. They chose to continue the pregnancy with comfort and palliative care after her birth.

At delivery, Susana was moderately depressed and received only noninvasive therapy, including drying, stimulation, and blow-by oxygen. The family was discharged from the hospital with hospice care. She had difficulty feeding and breathing because of severe micrognathia, requiring 24-7 parental monitoring and constant displacement of her mandible to prevent airway obstruction.

At 3 weeks of age, Susana developed progressive hydrocephalus, and a palliative ventriculoperitoneal shunt (VPS) was offered. The family initially agreed to surgery but maintained their resolve that their goals were limited to comfort care, including do not resuscitate (DNR) and do not intubate (DNI) orders. Three days

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before the scheduled surgery, she developed worsening hydrocephalus and seizures with cyanosis. She was brought to the emergency department (ED) where intravenous access was obtained and antiseizure therapy was begun, resulting in a cessation of seizure activity. Her airway remained tenuous. To facilitate seizure control and ease care for the parents, the neurologist and ED physician recommended a palliative VPS. The neurosurgeon was reconsulted, and he agreed to perform the procedure urgently.

After reviewing the history and examining the infant, the anesthesiologist began the informed consent process with the parents. The likelihood of difficult intubation (due to severe micrognathia) and the possible need for emergent tracheostomy in the operating room (OR) were explained. Postoperatively, the infant would need to be admitted to the PICU with extubation only when she was completely awake and free of seizure activity. The parents were not aware that surgery would require intubation or that there could be difficulty with intubation or the subsequent extubation. The anesthesiologist believed that the parents did not fully comprehend the relationship of the surgery to their goals of care and hence had given consent that was not adequately informed. As the consultant anesthesiologist, he experienced moral distress surrounding the need to provide information that had not previously been provided to the parents by the other physicians caring for their daughter.

#### **BERKLEE ROBINS, MD, MA, COMMENTS**

This case presents several challenges in determining what care plan is in the infant's best interest. These challenges are focused on both the best medical care of the infant as well as issues regarding the adequacy of informed consent. With regard

to consent, the parents clearly had not been given enough information to make an informed decision. However, the additional information that the anesthesiologist gave them put members of the care team in an uncomfortable position. The discomfort arose because of a lack of communication. A treatment plan was developed without involving the pediatric anesthesiologist and pediatric intensivist who would be involved in the care of the infant.

Veracity is at the center of the physician-patient (or parent) relationship. In this case, as in most (hopefully), there was no intentional deceit. Instead, it seemed there was an unintentional omission of information. Without this critical piece of information, the parents chose an intervention that they did not truly understand.

The anesthesiologist had ethical, medical, and legal obligations to disclose the additional information to the parents, although this potentially placed the anesthesiologist at odds with the other physicians caring for the child. However, he, like all physicians, had primary duties to the patient (and in this case, the parents). This led him to raise questions that they had not considered, causing him to appear to be suggesting a different course of treatment than the one previously proposed and agreed on, even if that was not his intent.

The informed consent process includes discussing the procedure and any alternative procedures (including nonintervention) that are medically available, legal, and ethically defensible. Risks and benefits are discussed, and finally questions are solicited from the patient or their surrogate decision maker (SDM), which is a parent or legal guardian. The ability to make an informed decision requires that parents have all the information that they need and want. In most cases, the information that is given to the parents does not vary significantly

from case to case and is based on the child's medical condition and the proposed surgical procedure. However, when a cure is no longer an option and a procedure is being considered for palliation or symptom alleviation, it is important to ascertain the parental goals of care. In this case, the parents were faced with a difficult moral dilemma. They were fully aware of the gravity and ultimate outcome of their child's illness but uncertain as to what course of action was in their child's best interest.

Interventions at the end of life that are goal directed can be ethically prohibited, ethically required, or ethically permitted, depending on the benefits and burdens of the procedure and their relation to the parents' goals and their determination of what is in the best interest of their child.<sup>1</sup> It is imperative that decisions always be consistent with the infant's best interest rather than in the SDM's best interests. In addition, medically futile procedures (however defined) are unlikely to be considered in the child's best interest. There is no medical (or ethical) obligation to offer parents nonbeneficial procedures, even when the SDM requests that everything be done. Those requests never justify nonindicated procedures, and professional codes support physicians in their responsibility to always act in a patient's best interest. However, there may be psychological or spiritual benefits that could be considered when weighing the benefits and burdens of a procedure.<sup>2</sup> The assessment of these benefits can be even more difficult than of the medical pros and cons. This is where focusing on the goals of the parents can be helpful in steering the informed consent process in a direction that is most helpful for them.

This case was difficult not because the parents were unclear of their goals but rather precisely because they were clear of their view of what

was best but were unsure of how to achieve it.<sup>3</sup> They knew that their child was going to die. They wanted to spare their child pain. However, without a clear understanding of the nature of the procedure (that it would require intubation and possibly a tracheostomy if the airway could not be secured via intubation with an oral endotracheal tube), they agreed to a plan that was not entirely consistent with their broader vision of what was best. As a result, the anesthesiologist had to slow things down and revisit the informed consent process. This was troubling for the anesthesiologist and upsetting for the parents, who were already severely stressed by the recent onset of seizures in their child. The anesthesiologist recognized both the benefits and risks of the palliative VPS, which included both the risks of anesthesia and the probable difficulties that would arise postoperatively in the PICU in which he anticipated an inability to wean the infant from a ventilator and successfully extubate.

### ADAM BOOSER, MD, COMMENTS

Anesthesiologists frequently take care of patients at the most critical stage of their illnesses. We are regularly confronted with ethically challenging situations. These challenges frequently occur when there is limited time to deal with pressing medical problems.

Cases like Susana's are unfortunately not uncommon in a busy tertiary pediatric hospital. Her case presents 3 major ethical questions:

1. How does the anesthesiologist deal with Susana's DNR and DNI orders in the OR and in the immediate recovery period?
2. Did Susana's parents receive adequate information from the physicians involved during the

consent process before being seen by the attending anesthesiologist?

3. Are Susana's best interests being served by the course of action set in motion before being seen by her anesthesiologist?

DNR and DNI orders present the need for significant consideration when obtaining informed consent and permission. This can be especially complicated in pediatric practice and is even more complex in emergent situations.

DNR and DNI orders "are written with the assumption that cardiopulmonary arrest will be a spontaneous event that is the culmination of the dying process of a child who has a terminal illness or a poor quality of life."<sup>4</sup> However, this presents anesthesiologists and surgeons with a unique problem.

The surgical procedure and administration of anesthesia themselves can cause a degree of hemodynamic and respiratory compromise that can result in complete arrest if certain protective and life-saving measures are not employed. The use of these measures (such as intubation and/or ventilation and vasoactive medication administration) will inherently violate explicit parts of most standing DNR and DNI orders.

In Susana's case, intubation and ventilation will be required to successfully and safely get her through her surgical procedure. Anesthesia must be provided to ensure an adequate lack of sensation, paralysis, amnesia, and unconsciousness. This level of anesthesia will have hemodynamic effects that may require certain intervention (eg, vasoactive medications).

Susana's medical team (including the attending surgeon and anesthesiologist) should compassionately discuss the entirety of her perioperative plan. This needs

to include a full discussion of the risks of the surgical procedure and of the anesthesia care needed to safely facilitate that procedure, including care in the recovery room and in this case the PICU.

The surgical procedure (a VPS) was one that would likely prolong her life. For stable and healthy patients, these procedures are not lengthy or complex cases, and they have low estimated blood loss and a mild to moderate postoperative pain trajectory.

However, Susana had multiple medical problems that would increase her surgical and anesthetic risk. She had a difficult airway that would make intubation (necessary for the procedure) and eventual extubation potentially challenging, risky, or impossible. She exhibited signs of a worsening neurologic state that might have had hemodynamic and respiratory consequences during the case and might have impeded her removal from mechanical ventilator support.

There was a real possibility that Susana would need postoperative mechanical ventilation for a period of time in the PICU or that she might even need tracheostomy with permanent ventilator support as a result of the palliative shunt procedure. The anesthesiologist correctly anticipated this risk, which had not been shared with the parents.

There are several options for how to deal with DNR and DNI orders in the perioperative period. DNR and DNI orders can be suspended for the OR and the immediate postoperative recovery interval. Alternatively, they can be altered with procedure-limited or goal-oriented approaches, or the standing DNR and DNI orders can be fully honored in the OR.<sup>5</sup> Susana's parents must be made aware of their options and of the anesthetic and surgical requirements for this particular procedure. If they

decide to proceed, then the DNR and DNI orders will need to be altered to fit the goals and expectations that Susana's parents have for their daughter in relation to the anesthetic and surgical requirements.

The anesthesiologist and the surgeon should not forget to facilitate a full discussion of the finalized intraoperative plan with all members of the surgical team, including the OR nurses. This will help to preemptively resolve any moral and ethical distress that could come from taking part in Susana's case.

Susana's parents' lack of understanding of the proposed surgical procedure and required anesthetic considerations as well as any resulting consequences (eg, tracheostomy) is not an uncommon scenario for anesthesiologists. In emergent situations, the informed consent process may be inadequate.

Insufficient communication can occur for a number of reasons. It can occur because the consent for the surgical procedure was obtained by a surgical resident with little experience and knowledge of what to expect in the OR. Susana's neurologist and the ED physician may not have been well informed of the correct and necessary anesthetic plan for this kind of case. It could also occur if nobody wanted to tell Susana's parents the bad news that she may never be able to come off the ventilator or that she may need a tracheostomy postoperatively.

Ideally, anesthesiologists should play a critical role in the whole informed consent process. However, they are often placed in the position of having to deal with complicated informed-consent issues during an intense and brief time before cases like Susana's. The pressure of time can make an already stressful situation even more so, which makes it difficult for an anesthesiologist to effectively communicate with emotionally distraught parents even when the

parents are capable of understanding the information being given them.

In the best of all possible worlds, Susana's anesthesiologist and surgeon would agree (if possible) on what the risks are and would meet together with her parents. They would take the time necessary to enable her parents to understand the relationship of the surgery and anesthesia to the goals of care Susana's parents wished for their daughter.

But the best of all possible worlds often remains just that: only possible.

The problem in this case was that the negative outcomes that might have resulted from the proposed procedure, if fully understood, might have changed the decision by Susana's parents for the surgery. If Susana was not able to come off the ventilator, the suffering involved with mechanical ventilation, prolonged hospitalization, and tracheostomy would make her parents' goal of comfort care unobtainable. If her parents had understood this, it might have changed their decision to have Susana undergo the surgery. They may have decided to simply continue comfort care only and take their daughter home again.

Anesthesiologists are uniquely experienced and knowledgeable to be the "gatekeepers" of the OR. We are often the last step in the informed consent process and the last physicians to see patients and their families before going to the OR. Anesthesiologists are critical to any decision-making process because we are uniquely positioned to see the entirety of medical care needed for our surgical patients.

### OUTCOME OF THE CASE

In a lengthy discussion with the parents, the anesthesiologist tried to shed light on the nature of the proposed surgery. He discussed transportation to the OR, induction

of anesthesia, the surgical procedure, and the likely course in the postoperative period in the PICU. The parents reaffirmed their desire to focus on quality of life and the alleviation of pain and suffering. They reluctantly chose full suspension of the DNI and DNR orders and treatment of the seizures and hydrocephalus with a palliative shunt as the best way to achieve that goal. The mother stated, "We don't want to sit around and do nothing."

The anesthesiologist and nurses experienced moral distress over the belief that the treatment plan lacked a clear resolution but respected the parents' authority to make the decision they felt was best for their child. Their goal was to allow the child to return home by treating the hydrocephalus and seizures. The surgery could then be considered ethically permissible as a way of achieving an ethically justifiable goal. Nevertheless, it was ethically problematic because there was no plan for postoperative care if the child could not be extubated.

The infant ultimately endured a painful surgical procedure. Postoperatively, she remained intubated, agitated, and sedated in the PICU. After a failed extubation, the parents considered a tracheostomy and gastrostomy. During that time, the parents were able to arrive at a place where they realized that additional medical treatment no longer served their child's best interests and thus did not meet their goal of care. They requested the withdrawal of medical therapy. The infant was subsequently extubated. She died in her parents' arms with additional sedation to alleviate air hunger and suffering.

It remains undetermined whether the surgical procedure was in the best interests of the infant at the time.

In retrospect, although the surgery could be construed as surgically futile in the sense that it prolonged dying, it may have served an important function for the parents, who felt like they did not abandon their child.

In complex medical situations, it is imperative that all members of the team have the opportunity to communicate with each other and the family so that parents have all the information they need to make the choices that are most effective in achieving their goals of care. In this case, a family conference with all specialists present may have led to a different decision by the parents and may have spared the infant a week of suffering before her death.

#### **JOHN D. LANTOS, MD, COMMENTS**

As Dr Booser notes, we live in the real world and not in the best of all possible worlds. In the real world, multidisciplinary care conferences are difficult to arrange. As a result, parents are often told different things by different doctors. Sometimes, those mixed messages are not problematic. After all, sometimes doctors disagree about diagnoses

or prognoses. Parents have a right to know about these professional disagreements and then decide whom to trust. However, parents sometimes simply do not understand the risks of proposed treatments. As Dr Robins notes, this is usually not because of anybody's intent to deceive. Instead, it is because the information is complex and is presented at a time of maximal emotional stress when people's cognitive processing may not be at its best.

The key take-home lesson of this case is that the health care professional is not merely a technician. All health professionals have ethical obligations to ensure that the parents of patients understand their options. In a culture of quality and safety, everybody is empowered to call attention to medical errors. Parental consent based on misunderstood information is a problem of quality, safety, and accountability. The anesthesiologist did the right thing in revisiting the discussion of consent for surgery. As the case illustrates, such an approach does not necessarily change the outcome, but it shows respect for the parents and should be applauded.

#### **ABBREVIATIONS**

DNI: do not intubate  
DNR: do not resuscitate  
ED: emergency department  
OR: operating room  
SDM: surrogate decision maker  
VPS: ventriculoperitoneal shunt

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