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Ethical and medical-legal dilemmas frequently arise in the perioperative care of term and preterm neonates. This requires that pediatric anesthesiologists have a working knowledge of these ethical concerns in order to provide comprehensive care. Here we provide a concise review of common ethical challenges in the perioperative care of term and preterm neonates utilizing a widely accepted decision-making framework and then examine fundamental medical-legal concerns in neonatal care.

Reasoning About Ethical Concerns

The Four Principles Approach to Ethical Reasoning

In their landmark text *Principles of Biomedical Ethics*, bioethicists Tom Beauchamp and James Childress advocate that ethical dilemmas in clinical practice are most comprehensively considered by utilizing a framework structured upon four principles: autonomy, non-maleficence, beneficence, and justice [1]. That is, when confronting a difficult ethical dilemma in clinical practice, the four principles framework advocates that the clinician determines how to proceed by assessing the net balance of the salient concerns from the perspective of each principle. Notably for pediatric practitioners, the conceptual foundation of this framework rests on the perspective of the autonomous adult patient, and thus the four principles framework does not entirely transfer to all pediatric contexts. Nevertheless, the four principles frame-

work is widely utilized by adult and pediatric bioethicists when resolving difficult ethical issues in the care of patients. Accordingly, it behooves the practicing pediatric anesthesiologist to be familiar with these concepts.

Limitations to the Four Principles Framework

Autonomy, from its Greek roots, literally means self-rule and is in many respects the foundation of the four principles framework. In ethics, autonomy commonly refers to an individual's freedom from control and their unconstrained ability to make profound life choices as they see fit. In the case of the neonate who has not developed the capacity to reason and make independent decisions about life choices, there can be no literal interpretation of this principle. Moreover, as mandated by legal regulations in nearly all US jurisdictions, and as supported by most pediatric ethicists, even loving parents are not free to autonomously make *any and all* medical decisions for their children, such as the refusal of blood component therapy in a life-threatening situation [2, 3]. Importantly, then, the foundational principal of autonomy or self-determination does not unequivocally reside even in parental decisions for their child. Parental autonomy is superseded, in part, by societal norms and standards to protect the minor as established by the Supreme Court of most countries.

Non-maleficence refers to the obligation of caregivers to avoid harm. In some clinical situations, agreement on what constitutes a harm would engender little debate, for example, failing to provide any perioperative analgesia to an infant suffering from significant pain after an invasive procedure would be considered a great harm by nearly all in our society. In other cases, such as a study requiring serial heel sticks in otherwise healthy neonates to study glucose trends, well-intended clinicians might reach opposite conclusions on whether such a research protocol represents, or does not represent, a harm [4]. The principle of *beneficence* is a continuum with non-maleficence but requires more of clinicians (and others) than not causing harm. The principle of

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beneficence requires clinicians to take active steps to ensure a positive benefit to the patient. Beneficence also includes the obligation to rescue persons from harm or harmful situations. This principle is interpreted from a translation of Hippocrates from his *Epidemics*: “As to disease, make a habit of two things, to help but at least do no harm.” Yet, as with “harm,” well-intentioned clinicians might not always agree on what constitutes a “benefit” in a particular clinical context. For example, some clinicians in a given context may strenuously advocate for continuing life-sustaining treatment because they conclude that the benefits outweigh the harms, whereas others may be equally certain, after assessing the same situation, that the harms of further treatment outweigh any potential benefit. The fourth principle, *justice*, refers to the provision of fair, equitable, and appropriate treatments to persons in light of what is owed to persons. As with the other principles, the concept of what constitutes justice is not free from differing interpretation by thoughtful clinicians or parents. Furthermore, the use of justice as an ethical principle is made more complex by the consideration of fairness and equality with respect to society, which may be especially challenging in cases involving scarce or financially burdensome resources. In sum, while the four principles approach to reasoning about ethical dilemmas provides a framework for clinicians to think comprehensively about all of the salient features, it cannot overcome variable interpretations of each of the principles that may prevent all parties to a given case from reaching similar conclusions on how to proceed.

Perioperative Applications of the Four Principles Framework

Autonomy

The biomedical principle of autonomy mandates informed consent to medical procedures for the adult with decision-making capacity. In the ideal process, the informed consent covers the risks and benefits of the proposed procedure, the risks and benefits of alternatives to the procedure, and the risks and benefits of doing nothing. In care of the neonate, parental permission necessarily replaces direct informed consent. True informed consent requires more than a signature on a closely typed form. The parents who give permission to caregivers must themselves understand the information, accept the care plan, and give voluntary permission without persuasion or manipulation.

The preanesthetic conversation, while often cursory, can and should be an opportunity for the pediatric anesthesiologist to inspire confidence and build rapport with the family as well as glean any important details about the infant before the procedure. Even for urgent or emergent cases, the parents have likely met and spent time with the surgeon. The pedi-

atric anesthesiologist, however, often meets the family only immediately before the start of the procedure. This meeting may even take place in the holding area, not the ideal location or timing for an in-depth discussion of the risks, benefits, and options for anesthetic care.

The content of the informed permission conversation with the parents must be adapted to the context. In cases involving full-term neonates scheduled for relatively elective or urgent procedures such as pyloromyotomy, circumcision, or herniorrhaphy, it very well may be that the risk, small as it may be, from the provision of anesthesia is significantly greater than that posed by the surgical procedure itself. The parents may express their concern to the pediatric anesthesiologist in these situations with statements such as: “My baby is not likely to suffer from his hernia repair, but I am very worried about the anesthesia.” Discussion of the possible deleterious effects of various anesthetic medications on the developing central nervous system is an important and frequently cited parental concern, which is reviewed in more detail beyond this chapter. In addition to a review of this issue and other relevant anesthetic concerns, the pediatric anesthesiologist should engage in a frank and understandable exchange with the parents, asking open-ended questions and providing them with time and space to weigh all of their concerns regarding the anesthetic.

Many surgical cases involving neonates are much more significant and emergent in nature, however. In these cases, often involving preterm neonates, the risks from the condition afflicting the neonate and from the surgery itself may be quite significant, reducing the anesthetic care to a resuscitation more than the provision of analgesia, unconsciousness, and vital sign stability. The question of cardiopulmonary resuscitation (CPR) may even be part of the preanesthetic discussion. In such cases, the pediatric anesthesiologist should have a discussion with both the surgeon and neonatologist in order to appreciate the gravity of the neonate’s condition and what can be expected in the operating room. It may be appropriate to have a preanesthetic discussion with the parents, surgeon, and the neonatal intensive care unit physicians and nurses in order to minimize the chances in this very stressful situation that the family becomes confused and unduly anxious as a result of hearing similar information, but with different emphasis and language from different sources. In consideration of difficult cases like these, Pinter has proposed classifying surgical neonates according to their chances for recovery and the quality of life should the neonate recover [5]. The details of the classification are not as important as ensuring that the parents understand, as much as possible, the immediate as well as longer-term prognosis, all before signing the consent. Other authors, such as Caniano, reviewed neonatal surgery and highlighted the important differences between simply survival and a benefit to the neonate [6],

whereas Lorenz reviewed the important ethical considerations in the management of preterm neonates at the extremes of viability and indicated the primacy of the neonate's best interest in these difficult choices [7]. Parents are considered by all of these commentators to be the persons best suited to determine and advocate for the best interests of their neonate, once again underscoring the importance of the preanesthetic discussions.

Non-maleficence

The principle of non-maleficence comes into importance especially in the care of neonates at the extremes of viability and/or with such serious surgical conditions that survival is in doubt and prognosis grim. Harm, as defined by Beauchamp and Childress, means an unjustifiable setback or defeat of a person's interests [1]. They also limit their definition to physical harms. As mentioned, parents are generally, but not unequivocally, considered the *prima facie* authority to determine the best interests for the neonate. Yet, some have argued that the best interest standard is insufficient for severely impaired infants and instead advocate for additional viewpoints in the evaluation of care provided to these unfortunate neonates [8]. Proponents of this view argue that the suffering of infants is not given sufficient weight and propose that severely impaired infants have the right to a dignified death and support palliative as opposed to intensive care for these unfortunate patients.

The Committee of the Fetus and Newborn (COFN) of the American Academy of Pediatrics (AAP) addressed the issue of determining an infant's best interests. In a policy statement on high-risk neonates, the Committee notes, "...intensive treatment of all severely ill infants may result in the prolongation of dying accompanied by significant discomfort for the infant or survival with unacceptable quality of life...non-intensive treatment may result in increased mortality and morbidity...either approach risks undesired and unpredictable results" [9]. The COFN also notes the importance of the parents' role in decision-making regarding the care of these critically ill neonates but also reemphasizes that the physician's first responsibility is to the patient. The Committee further states that physicians are not required to provide treatment that they consider to be inappropriate or to withhold beneficial treatments [10]. In cases of honest disagreement, the COFN recommends that the hospital bioethics committee become involved to resolve the issues. In practice, there may be insufficient time for this to occur, and the pediatric anesthesiologist must personally decide if their personal morals allow them to participate in the care of a particular neonate. Last, the Committee's policy statement notes the following:

- In cases where there is little or no chance for survival, CPR should not be begun.

- In cases where survival is possible but a good outcome is unlikely, the (well-informed) parental preferences should guide whether or not CPR be instituted.
- In cases where a good outcome is considered more likely, CPR should be undertaken and continual reevaluation of the utility of continued intensive care be undertaken [10].

Beneficence

There are two aspects of beneficence: Positive beneficence requires that clinicians act to increase the welfare of patients, while utility requires clinicians to balance the benefits and burdens of an action and choose the action leading to the best overall result [1]. The utility aspect of beneficence becomes relevant to pediatric anesthesiologists in terms of assessment of the risks and benefits of appropriate anesthetic care for an operation or procedure and in the management of pain in the neonate in both intraoperative and postoperative periods [11]. The principle of utility serves as a useful decision-making framework in these situations since anesthetic agents have immediate deleterious cardiovascular effects as well as possibly longer-term effects on the developing central nervous system of the neonate. In the postoperative period, assessing the adequacy of analgesia can also be quite problematic. There are a variety of pain assessment tools available for the neonate for evaluation of acute, procedural, and chronic pain [12]. These tools include both physiologic and behavioral components and will be most effective only if all caregivers have ongoing training in their use. Yet even in the case of clearly suboptimal pain control, analgesics present both benefits and potential harms to the neonate. Careless use of analgesics in any neonate can lead to significant cardiopulmonary derangements. A proper balance of the benefits and harms of such essential treatment as adequate pain relief begins with clinically competent assessment of the patient and appropriate dosing of any medication.

In sum, ethical considerations of benefit and harm are inextricably linked to competent clinical care. This is particularly relevant to the provision of palliative care to infants with a life-threatening and/or terminal condition in which the unique training and expertise of the pediatric anesthesiologist can guide the development and implementation of effective treatment regimens with minimal untoward effects [13].

Justice

The concept of what constitutes justice in the context of healthcare is more problematic as there are widely differing views in our plural society. Barnum describes what she calls "benevolent injustice," an outcome in which an infant survives a difficult neonatal course but with significant morbidity such that they depend on significant technological support. She quotes Norman Daniel's definition of justice as it applies to healthcare as the maintenance of normal function

and then describes it as an injustice when healthcare fails in its primary function to maintain normal functioning of the individual neonate. Barnum elaborates that a benevolent injustice occurs when well-intentioned treatment leaves a neonate with significant morbidity and disabilities [14]. Recently, outcomes of perinatal care in the United States were compared with that in several other countries, including Australia, Canada, and the United Kingdom. Care in the United States differed from these other countries in providing proportionally less prenatal care but having proportionally more intensive care nursery capacity and expended significantly more resources on neonatal intensive care. Low birth weights were seen more often in the United States though the relative risk for overall neonatal mortality did not differ significantly among the four countries [15].

Case Example: In the case of the neonate born to a family of the Jehovah's Witnesses faith, the Supreme Court in both the United States and Canada have ruled that blood products cannot be withheld if the neonate's life is believed to be in jeopardy. The tacit assumption is that the child would follow the parent's religion and hence would refuse blood even in the face of death. However, the Supreme Court have ruled that this assumption may not hold true and until the neonate reaches the age of maturity to make such a decision, society must protect the child and provide the lifesaving treatment.

It has been the editors' experience through encounters with the Medical Liaison Committee of the Jehovah's Witnesses that when a face-to-face discussion takes place between the members of the Committee, the parents and the medical team, and the care team describes all efforts will be made to optimize the neonate before surgery, to implement all blood-saving measures and to minimize all blood loss during surgery, it becomes unnecessary to proceed to court to make the neonate a ward of the state for the period of the surgery. It has likewise been the editors' experience that following such discussions, although the parents may remain steadfast and refuse to consent to a blood transfusion for their neonate, they do understand and respect the efforts expended by the medical team to respect their beliefs and, in most circumstances, will consent to the anesthesia and surgery.

Perioperative Do-Not-Resuscitate Orders

Neonates with existing do-not-resuscitate (DNR) orders may require anesthesia for palliation or for placement of devices that simplify care such as a gastrostomy tube, tracheostomy, or central line. Underlying the decision to invoke a DNR order is typically the premise that the neonate has a terminal or irreversible condition and that a cardiac arrest, if it were to occur, will leave the patient in yet a worse condition, even if

the resuscitation were successful. DNR orders are most often established when the parents have already decided to limit care or when a cardiac or respiratory arrest has previously occurred; these orders precede death by a matter of days on average [16]. Accordingly, resuscitation in this context is not warranted. Yet, this premise does not hold in the perioperative setting because anesthetic medications inherently induce some degree of cardiorespiratory instability, which anesthesiologists expect and are present to ameliorate, if not reverse.

The American Society of Anesthesiologists (ASA) has promulgated recommendations for the care of patients with a DNR order who undergo anesthesia [17]. These recommendations strongly disagree with routine suspension of the DNR order for patients undergoing anesthesia for procedures and instead endorse a discussion among the caregivers and family members before the procedure on the overall goals of care and the extent to which resuscitation measures will be applied.

More recently, the American Academy of Pediatrics has also put forth a statement advocating a similar approach [18]. This report describes three approaches to DNR orders for children who come to the OR for anesthesia and surgery: full resuscitation, a goal-directed approach, or a procedure-directed approach. The informed consent process assumes particular importance in these cases as it is likely that neither the surgeon nor the anesthesiologist was involved in the decision to invoke the DNR order. During the preanesthetic visit, the presence of the child's primary neonatal physician as well as the surgeon would ensure that all members of the medical team participate in a discussion with the family to reach a congruous approach to the DNR order in the operating room.

With the procedure-directed approach to anesthetic care of these neonates, the details of intraoperative care must be carefully reviewed with the family. If the trachea is not intubated, but the procedure would generally be done with an anesthetic technique that would include tracheal intubation, this must be discussed in detail with the family. In addition, other possible eventualities that would be routinely managed in the provision of an anesthetic and that would otherwise be considered resuscitation such as stabilizing abnormal vital signs and rapid administration of intravenous fluids, blood, or blood products must be reviewed.

Others have advocated for a goal-directed approach to the anesthetic care of children with a DNR order in place [19]. In this approach, the medical details of perioperative care are less important than understanding and respecting the goal of the family vis-à-vis the procedure. This approach does not specify the details of anesthetic care as they are specified in the procedure-directed approach. Rather, the concept here is to utilize any techniques that are consistent with the overall goal of care that is established in the preanesthetic meeting

with the family. An additional concept of great importance in this context is that whenever a DNR order is transiently altered in order to perform a procedure, whether suspended, or a procedure-directed or goal-directed approach is adopted, it is essential to clearly define a priori when these changes will commence and when they will cease. Advanced agreement among the parents and caregivers on the timing for resumption of the DNR order must be respected unless all parties agree that circumstances warrant revision of the pre-anesthetic treatment plan. Failure to do so is a certain recipe for ethical conflict.

In addition to specific approaches to discuss perioperative DNR orders, pediatric anesthesiologists, along with neonatologists and pediatric surgeons, benefit from use of a shared decision-making (SDM) model [20, 21]. This methodology has been widely published and is a helpful model for the perioperative care of critically ill neonates. There are challenges to its use, however, in situations when the parental values and the neonate prognosis are uncertain. These choices are often made in very emotionally stressful moments further complicated by, in many cases, the pressures of time [22]. Leaders in the field describe utilization of the “best interests of the child” standard or the more comprehensive biopsychosocial framework to guide discussions with parents and to weigh benefits/risks of different interventions [23].

Regulatory Concerns in Perinatal Care

The Baby Doe Regulation Controversy

Few regulations have generated as much confusion and controversy as the so-called “Baby Doe” regulations [24]. Baby Doe was an infant with Down syndrome and tracheoesophageal fistula born in Bloomington, Indiana, in 1982. His parents declined corrective surgery on the grounds that he would never achieve a “minimally acceptable quality of life,” and the child subsequently died. The case generated public controversy. After a number of appeals, the final Baby Doe regulations, often referred to as the “Final Rule,” were passed by the Congress as the 1984 Amendments to the Child Abuse Prevention and Treatment Act [25]. This legislation required all states to create a regulatory system to investigate cases where medically indicated treatment is withheld from handicapped infants or states would risk the withholding of federal funding for children’s services. It also stipulated that “the withholding of medically indicated treatment from a disabled infant with a life-threatening condition” by parents or providers was considered medical neglect. The legislation then outlined three medical conditions that would justify withholding otherwise required treatment. According to the

Final Rule legislation: “The term ‘withholding of medically indicated treatment’ means the failure to respond to the infant’s life threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician’s reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician’s reasonable medical judgment any of the following circumstances apply:

- (i) The infant is chronically and irreversibly comatose;
- (ii) The provision of such treatment would merely prolong dying, and not be effective in ameliorating or correcting the infant’s life-threatening conditions, or otherwise be futile in terms of survival of the infant; or.
- (iii) The provision of such treatment would be virtually futile in terms of survival of the infant and the treatment itself under such circumstances would be inhumane.” [26].

Many argue that the Baby Doe regulations are not helpful in decision-making for infants because of ambiguity regarding the term “appropriate.” Regardless of how one interprets the intentions of the Final Rule legislation, this is not a commonly recommended framework for ethical decision-making at the end-of-life in the child. The American Academy of Pediatrics (AAP) Committee on Fetus and Newborn (COFN) describes the foundations upon which difficult decisions about resuscitation rest: clear, open communication between the healthcare team and the family, active involvement of the family in decision-making, continued care when ICU care is stopped, and finally, that treatment be guided by the best interests of the child [9]. In a more recent clinical report, COFN again emphasized the importance of individualized consideration of all factors by the care team and the parents before reaching a decision about resuscitation [10]. Other commentators have noted that the literal interpretation of the regulation mandates the treatment of all critically ill neonates under all circumstances, and even possibly against the wishes of loving and informed parents, and the professional opinion of the clinicians, leading to permanent care of all infants, no matter how devastated and compromised. Few would agree that such an inflexible approach to every infant’s care is wise [27].

Born Alive Infant Protection Act

Subsequent to the Baby Doe regulations, the Born Alive Infant Protection Act (BAIPA) was passed in 2002. This law

extends the definitions of “person” or “child” to include “every infant member of homo sapiens who is born alive at any stage of development” [28]. Sayeed quotes from the deliberations that the law was enacted “to repudiate the flawed notion that a child’s entitlement to the protections of the law is dependent on whether that child’s mother or others want him or her” [29, 30]. Later, in 2005, the Department of Health and Human Services announced that enforcement of regulations was affected by that law (BAIPA) with mention of the Emergency Medical Treatment and Active Labor Act (EMTALA). The EMTALA statute requires medical practitioners and institutions to provide care to individuals with an emergency condition regardless of that individual’s ability to pay. Taken together, these two acts could restrict or eliminate any practitioner or parental discretion regarding resuscitation of very low gestational age neonates. There is much confusion about the exact meaning of the regulations, and various interpretations of the regulations have been published. The AAP COFN, in their policy statement Noninitiation or Withdrawal of Intensive Care for High Risk Newborns, does not mention these regulations [9]. The AAP Neonatal Resuscitation Steering Committee commented in a letter to the editor in *Pediatrics* that BAIPA “should not, in any way affect the approach that physicians currently follow with respect to extremely premature infants.” [31] The AAP Committee on Bioethics, in their statement Ethics and the Care of Critically Ill Children, opined that physicians may have more discretion in redirecting care of critically ill neonates than is commonly realized, citing exceptions to the mandate to provide treatment except in cases where it is “futile” or “virtually futile” [10]. Other authors have similarly noted the unique “zone of parental discretion” that exists in the case of neonates at the extremes of viability, where a parental decision to either palliate or to aggressively resuscitate is equally ethically defensible [32]. The AAP further supports the importance of parental involvement in these difficult life and death decisions along with the reasoned medical judgments of the newborn medicine physicians [9, 10].

Conclusions

Superb anesthetic care of neonates requires an extensive knowledge of the unique physiology of these, our smallest and most vulnerable patients. Yet, this alone is insufficient to the provision of comprehensive care of the neonate. The pediatric anesthesiologist must equally have a working knowledge of the ethical and regulatory concerns peculiar to the neonate. In nearly all instances, clear and open communication with the parents and the neonatal medical team will identify issues of ethical concern and pave the way to determining the optimal prescription for each neonate.

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