



## Ethical Considerations in the Neonatal Intensive Care Unit

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### ABSTRACT

Advances in treatment and technology capabilities, coupled with the ability to care for younger, smaller, and sicker neonates contribute to ethical conflicts in the neonatal intensive care unit (NICU). Although the ethical approach to care is sometimes inconsistent, it is important for clinicians to develop and adopt a framework for ethical decision-making in the NICU. Providers need to understand the four ethical principles of autonomy, beneficence, nonmaleficence, and justice and apply these principles to clinical decision-making about care in the NICU. Ethical decision-making must be family-centered and respectful of cultural differences. Providers must comply with professional ethical guidelines as well as government and legal mandates. Adopting ethical frameworks for neonatal care ensures a more holistic approach to care in the highly technical environment of the NICU.

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Advances in treatment and technology capabilities, coupled with the ability to care for younger, smaller, and sicker neonates contribute to ethical conflicts in the neonatal intensive care unit (NICU). The perspectives on ethical issues in the NICU vary and no consensus exists on a consistent approach to resolving these conflicts.<sup>1</sup> Clinical and ethical experts emphasize the need for a consistent framework for applying ethical principles in the NICU. This article provides an overview of ethical issues in the NICU. The four principles of ethics are described and applied to situations in the NICU environment. Recommendations for practice follow to assist nurses in developing and accessing an ethical framework for care in the NICU.

### Overview

Sophisticated technological advances to treat the most critically ill neonates outpace clear ethical standards and approaches for NICU care. Historically, care providers have treated critically ill neonates first and reflected on the ethics of treatment later. Fortunately, ethical considerations of care are beginning to precede interventions even though no uniform approach to ethics decision-making in the NICU exists.<sup>1</sup> Ethical conflicts in the NICU often surround provision of treatment and withdrawal of treatment.<sup>2</sup> Conflicts arise from the differences in ethical perspectives of the decision-makers, whether they are physicians, nurses, parents, alone or in combination. Regardless of who the decision-makers are, ethical decisions in the

NICU can have a profound effect on neonates, families, physicians, nurses, and society.<sup>3</sup>

The need to base ethical decisions on evidence is growing, and care providers are seeking consensus on best practices for these difficult decisions.<sup>3</sup> Frameworks for ethical decision-making in the NICU are available, though none are used consistently.<sup>1</sup> Regardless of the particular frameworks, a clear understanding of the principles of ethics provides a foundation for ethical decision-making in the NICU. Table 1 provides a summary of the four ethical principles. The four ethical principles are autonomy, beneficence, nonmaleficence, and justice; each is described below in more detail.

### Autonomy

The ethical principle of autonomy refers to self-determination and encompasses veracity, disclosure/informed consent, confidentiality, and promise keeping.<sup>4</sup> Applying the principle of autonomy to ethics in the NICU creates a challenge. First, infants cannot make autonomous decisions; therefore, parents make autonomous decisions on behalf of their babies. Next, conflicts arise from the varying perspectives from which to present medical information to parents. Considering the principle of autonomy, experts agree disclosure of evidence-based information and consideration of family values is a reasonable approach.<sup>1</sup> By providing parents with the most current evidence-based knowledge about the condition and prognosis of their child and assuming parents will act in the best interests of their child, providers demonstrate respect for autonomy.

Conflicts arise when providers and parents disagree about the best interests of the infant. The mother who plans to breastfeed her infant feels a loss of autonomy when she is told her 24-week infant with severe respiratory distress syndrome cannot directly breastfeed. She insists the baby must at least receive colostrum as soon as possible

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**Table 1**  
Summary of Ethical Principles (4).

Autonomy	Self-determination; encompasses veracity, disclosure/informed consent, confidentiality, and promise keeping
Beneficence	Acting from a spirit of compassion and kindness to benefit others
Nonmaleficence	Non-harming or inflicting the least harm possible to reach a beneficial outcome
Justice	Acting out of fairness for individuals, groups, organizations, and communities; includes fair allocation of and access to health resources

despite plausible explanations about her baby's immature gastrointestinal system, risks for necrotizing enterocolitis, and aspiration pneumonia. The mother feels a loss of autonomy over the care of her baby. Although direct breastfeeding is counter-indicated for the baby, the nurse supports the mother's autonomy by encouraging her to use a breast pump so her breast milk can be frozen and used when the infant is ready for enteral feedings. In some NICUs, colostrum is used routinely for mouth care in the days before an infant is ready to begin enteral feedings.<sup>5</sup> Teaching the mother to bond with her baby using this method during the time before the start of enteral feedings can increase her sense of autonomy. During the crisis of preterm birth, clinicians can address the ethical principle of autonomy by offering alternative ways for the mother to engage in care for her infant.

Disclosure of objective evidence to aid parent decision-making is as important as respecting the cultural and moral beliefs of parents in making autonomous decisions.<sup>2</sup> Cultural differences between families and providers can result in decision-making challenges, restricting autonomy for families. A 26-week preterm infant of a Jehovah's Witness family requires red blood cell transfusion for symptomatic anemia. The family opposes the transfusion on the basis of their religious beliefs. The providers collaborate with the family to understand better the effects of anemia, to recognize symptoms, alternatives to red blood cell transfusion, and the point at which transfusion is necessary. Disclosure of information in a culturally sensitive manner allows the parents to engage as equal partners in the decision-making process.

### Beneficence

Beneficence refers to acting from a spirit of compassion and kindness to benefit others.<sup>4</sup> Nurses and physicians must view beneficence from the perspective of the patient and families. Parents and providers may disagree on the benefits of treatment and potential outcomes. Nonetheless, beneficence guides providers to consider and respect the viewpoints of the parents, even when those viewpoints seem at odds with provider values.<sup>2</sup> Consider the same example of the baby with symptomatic anemia whose parents are Jehovah's Witnesses. Although the providers recommend red blood cell transfusion for the infant, the parents decline transfusion on the basis of religious beliefs. By recommending alternative treatment options, absolute criteria for blood transfusion, and respecting the parent's beliefs, the clinicians demonstrate beneficence toward the family and simultaneously ensure the best care for the infant.

A confounding factor of beneficence and autonomy is the relative uncertainty and unpredictability of outcomes for sick neonates. Data provides a relative understanding of outcomes and expectations, but multiple individual factors determine outcomes for each neonate. Therefore, beneficence becomes a somewhat relative term from case to case.<sup>1</sup> A 40-week infant with persistent pulmonary hypertension of the newborn (PPHN) and Group B streptococcus pneumonia is on maximum ventilator settings with acidemia. The clinicians offer the parents the option of extracorporeal membrane oxygenation (ECMO) treatment for the infant. Although this is an indicated treatment for the infant, a favorable outcome is not guaranteed. The outcome statistics become part of the discussion with the parents. Together

with providers, the parents consider all the information and treatment options in terms of the best interest of the infant. Caregivers need to support and respect parents' decisions even when disagreements sometimes arise.

### Nonmaleficence

Nonmaleficence means non-harming or inflicting the least harm possible to reach a beneficial outcome.<sup>4</sup> Harm and its effects are considerations and part of the ethical decision-making process in the NICU. Short-term and long-term harm, though unintentional, often accompany life-saving treatment in the NICU.<sup>1</sup> Consider again the example of the infant with PPHN who is placed on ECMO treatment. Although ECMO can provide life-saving treatment for the neonate, this high-tech, high-touch treatment has high potential for harm from infection, fluid and electrolyte imbalances. Weighing the ethical principles of nonmaleficence and beneficence presents the question: What is in the best interest of the neonate to provide the best possible outcome with the least amount of harm? The potential iatrogenic effects of the NICU must always be weighed against the potential best outcomes.

The principle of nonmaleficence is also a consideration when treatment is futile. In this case, prolonging treatment is a violation of the principle of nonmaleficence. Conversely, the withdrawal of futile treatment and the institution of palliative care align with the principle of nonmaleficence.<sup>2</sup> Providers must question the potential harm and benefits of technology in cases of extremely premature and critically ill neonates whose prognoses are poor. Use of technology in these cases often inflicts further pain and suffering and will not lead to positive benefits. Consider the infant born with Trisomy 18, a genetic disorder considered incompatible with life. The principle of nonmaleficence in combination with the principle of beneficence guides clinicians in suggesting a palliative plan of care for the baby. This treatment option minimizes harm to the infant and prevents prolongation of futile treatment. However, it is also important to respect and support the wishes of the family who requests continuation of interventions. Weighing the needs of the family is sometimes the most challenging aspect of these types of situations.

Further, providers must consider the potential for harm from iatrogenic effects of treatment, particularly with long-term treatment, and must commit to reducing medical errors and harmful events.<sup>1</sup> The focus of reports from the Institute of Medicine regarding health care quality aim to reduce preventable harm to patients and improve favorable outcomes.<sup>6</sup> Considering the vulnerability of infants in the NICU, nurses and physicians must commit to reducing and limiting harm when providing care. This is especially true in the technology-intensive NICU environment.

### Justice

Justice refers to acting out of fairness for individuals, groups, organizations, and communities.<sup>4</sup> Providers often question the principle of justice when confronted with infants of parents with different values and lifestyles. When a preterm infant dies following years of infertility treatment for parents who desperately want a child and in the same NICU, a preterm infant suffers from crack withdrawal from a crack-addicted mother, providers are conflicted and question the ethical principle of justice. Regardless of the circumstances, nurses and physicians must provide compassionate, quality care to both infants and treat both families with dignity.

Justice also refers to fair allocation of services and resources. In a global sense, ethical conflicts arise when considering the ability to offer life-saving NICU services to an infant in one country, but the inability to offer the same services to a similar infant in another country. The limits of resources create ethical conflicts of justice.<sup>1,2</sup> Similarly, economic goals of health care organizations sometimes

conflict with the goals of care and treatment.<sup>4</sup> For example, NICUs are typically revenue-generators for hospitals with high third party reimbursement rates for NICU care. Allocation of funds to expand NICUs to reach organizational economic goals without consideration of the goals of neonatal care and the needs in the community is unethical under the principle of justice.<sup>1</sup> However, allocating funds for NICUs to provide equal and adequate access to necessary care that does not exploit community and organizational economic goals shows respect for the ethical principle of justice.

### Recommendations for Practice

Although ethical issues in the NICU can be challenging and ambiguous, practice recommendations assist nurses and physicians by offering guidelines from a common knowledge and evidence base. These recommendations derive from professional and government organizations, and include both clinical guidelines and legal mandates. To manage ethical dilemmas in the NICU consistently and proactively, and to assist families with ethical decision-making, familiarity with current best evidence, practice, and legal guidelines is important.<sup>1–3</sup> Providers must understand the four principles of ethics and how they apply to neonatal care. Recognizing how the ethical principles apply to ethical dilemmas in the NICU prepares providers to respond to complex situations with forethought. See [Table 2](#) for a summary of recommendations for practice.

To begin, surveying personal ethical beliefs and values helps neonatal nurses and physicians discover areas of potential ethical conflict and areas of alignment with others. Additionally, providers must begin to understand ethical beliefs and values of differing cultures. Considering the changing multicultural mix of the United States, understanding cultural ethical differences helps reduce ethical conflicts in the NICU. Surveying personal ethical beliefs and values and developing respect for cultural ethical differences enable providers to communicate better with colleagues and families and resolve ethical conflicts collaboratively.<sup>3</sup>

Staying abreast of current clinical treatment options and outcomes data ensure providers offer the best information to families during ethical decision-making discussions.<sup>3</sup> Utilizing current clinical knowledge and questioning clinical practices also helps providers improve and test care to ensure high quality and best ethical practices.<sup>1</sup> Combining clinical information with ethical perspectives offers a broad and more holistic view of care options.

Complex ethical issues in the NICU can lead to lingering moral distress among nurses and physicians. When ethical issues arise, debriefing sessions can be helpful to staff. Debriefing can provide a source of emotional support and learning to aid the process of ethical decision-making in the future.<sup>7</sup>

Fortunately, neonatal care providers do not need to engage in ethical decision-making without the support of national standards. From professional best practices to government directives and

laws, many ethical decisions are prescribed via guidelines, precedents, and mandates. For example, The American Nurses Association Code of Ethics provides ethical standards and expectations for all nurses. More specifically, the National Association of Neonatal Nurses and the American Academy of Pediatrics provide ethical guidelines for practice. Although ethical decision-making sometimes requires considerations on the basis of case circumstances, laws, federal guidelines, and professional best practices ensure a more consistent approach.<sup>3</sup>

True for all best practices in health care, clear and transparent communication with families regarding ethical issues in the NICU is essential. Providers must offer information in a way that is current, accurate, compassionate, respectful, culturally sensitive, and family-centered.<sup>1</sup> Assisting families with difficult ethical decisions is an important component of the role of neonatal nurses and physicians. Providers must engage families as equal partners in the decision-making process in a way that gives families the most respect and control over care decisions for their babies. Finally, consider the development and regular use of an ethics committee comprised of all stakeholders including families. The ethics committee serves an advisory role when confronted with challenging ethical issues in the NICU.<sup>8</sup>

### Conclusion

Consideration of the ethical principles of autonomy, beneficence, nonmaleficence, and justice in the NICU is imperative as capabilities and technology advances. The ability to provide life-saving technologies to smaller, sicker, and younger neonates outpaces ethical standards for care in the NICU. Although providers and ethical experts recognize the need to move ethical discussions to the forefront of care in the NICU, no standard framework exists for these discussions. Experts do believe an evidence-based, family-focused approach is the best approach for resolving ethical conflicts in the NICU.

The principle of autonomy urges providers to respect the cultural and ethical beliefs of parents in making care decisions in the best interests of their baby. By providing parents with evidence-based information and respecting their decisions to act in the best interests of their baby, providers can work collaboratively with families to honor the principle of beneficence.

The technology of care in the NICU often confronts the principle of nonmaleficence. When considering nonmaleficence, providers and parents must weigh the goals of care against outcome expectations and commit to reducing iatrogenic harm to neonates in the NICU. Respect for the principle of justice in the NICU is evident when allocation of funds reflects true community needs and the goals of care are not simply the economic goals of the hospital.

Ethical practice recommendations in the NICU include understanding personal ethical beliefs and values, and understanding differing ethical beliefs and values based on culture. Understanding the principles of ethics in combination with current clinical knowledge, professional guidelines, national standards, and laws helps providers offer families broad and holistic information for ethical-decision making. Disclosing information to families in a way that is culturally sensitive and family-centered ensures families the opportunity to make ethical decisions in the best interests of their babies. Debriefing sessions for staff following challenging ethical issues offers opportunities for support, learning, and guiding future ethical decision-making processes. The development and use of ethics committees comprised of all stakeholders including families offers advice and guidance for ethical decision-making in the NICU.

Care provision in the NICU is highly technical and stretches the limits of ethics. To engage in effective communication and ethical decision-making in the NICU, clinicians must address ethical beliefs and values with and between themselves, and understand the cultural

**Table 2**

Summary of Recommendations for Practice.

1. Understand the four principles of ethics: autonomy, beneficence, nonmaleficence, and justice and their application in the NICU setting.<sup>3</sup>
2. Survey the ethical beliefs and values of self and health care colleagues, and use the information as a basis for discussion of ethical decision-making practices.<sup>3</sup>
3. Consider staff debriefing sessions after an ethical issue is encountered.<sup>7</sup>
4. Understand and respect cultural differences in ethical beliefs and values.<sup>3</sup>
5. Regularly comply with professional ethical standards and best practices in the clinical setting to guide decision-making.<sup>1,3</sup>
6. Comply with federal and legal standards for ethical care.<sup>1,3</sup>
7. Adopt a family-centered approach to ethical decision-making.<sup>3</sup>
8. Consider regular use of an ethics committee comprised of all stakeholders including family representatives.<sup>8</sup>

ethical beliefs and values of patient families. In addition, clinicians must comply with professional and legal ethical standards of care. Solid understanding of the ethical principles of autonomy, beneficence, nonmaleficence, and justice in combination with providing current evidence-based neonatal care help guide nurses and physicians proactively when ethical conflicts arise in the NICU.

Ethical principles in combination with professional and legal practice guidelines provide an ethical framework for the highly technical and often ethically ambiguous NICU environment. Providers in the NICU must continually question and consider ethical principles when providing care to neonates because the technology of care is not always congruent with the ethics of NICU care and can have long-lasting effects on patients, family, providers, and society. Understanding ethical principles and abiding by ethical best practices helps neonatal nurses and physicians provide compassionate family-centered care with ethical forethought in the highly technical NICU environment.

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