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# Ethical Decision Making in the Neonatal Intensive Care Unit

by Pat Basto

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*Ethics should always guide our decision making in health care, but this becomes especially important when the medical options are limited. In the case of premature or critically ill newborns, decision making is complicated by the inability of the infant to participate in decisions. Choices must then be made by those with a primary interest in the infant's well-being. This includes the child's parents, the health care providers, and sometimes other persons as well. Acknowledging the relationships among patients, family members and health care professionals gives valuable information that can illuminate the specific case in question. It may also suggest options that would not otherwise have been considered. Broadening our perspective in this way potentially can lead to decisions which are more sensitive to the needs of everyone involved.*

In the majority of cases, the birth of a premature infant or a baby with severe birth defects is unexpected, and there has been no time or even a reason to prepare for what has happened. Parents of a critically ill infant will usually say, "Please do everything that can be done." And because they may have little real idea of what can be done, or what it will mean for their child, or for themselves and their family, they must depend on health care professionals either to make decisions for them or to guide them in making these decisions. Making treatment or nontreatment decisions for critically ill newborns is an unavoidable but extremely difficult task for health care providers in a neonatal intensive care unit, as well as for the parents of these children. We find ourselves looking not just at what *can* be done, but what *ought* to be done, and this is the source of much pain for nurses in the NICU. It has also been the impetus for me to explore clinical ethics, and to put some of my thoughts in writing.

## Who Should Decide?

To some extent, ethical confusion stems from the differing viewpoints of various individuals and organizations who provide or regulate services available to children. For instance, who should be responsible for making decisions for children? The debate about patient rights, and legislation such as the Patient Self Determination Act of 1990, which have focused primarily on the ethical principle of autonomy, have not addressed the needs of children and the health care they receive. Although children have moral status and legal standing independent of their parents, it is not possible to treat children, es-

pecially newborns, as totally separate individuals without their families. They cannot exist apart from the care of responsible adults, and in our society parents are usually presumed to be the appropriate surrogate decision makers for their young children. From a legal standpoint, treatment decisions for infants are commonly based on a "best interest of the child" standard, which looks at the child independently of his or her family. But from a social services perspective, providers focus on maintaining the integrity of the family rather than treating the child as an individual.

Moreover, in an effort to arrive at the best decision in the most reasonable way, health care professionals typically make great efforts to objectify an ethically sensitive situation. However, to expect parents of a sick newborn to display a similar objectivity is asking the impossible. And if health care professionals choose to ignore this fact, they will be doing a disservice to the children and families in their care.

Which viewpoint is most correct? I find there is some validity in all these attempts to determine who should decide for children. Must we choose one theory over another, or can we instead synthesize the best of all of them to arrive at an answer that is ethically acceptable?

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## Making Difficult Decisions

Clinical ethics has been defined by Brody and Tomlinson as "what ought to be done in a given situation, all things considered."<sup>1</sup> Principle-based analysis of ethical dilemmas emphasizes objective reasoning with a focus on conflicting rights or obligations. For instance, the principle of autonomy is generally based on freedom of the will, or the right to be self-determining. However, in the case of neonates this principle cannot be applied to resolve ethical dilemmas. Typically this "right" of autonomy shifts to the parents, and is often considered absolute, unless the parents' wishes with regard to treatment options differ from the treatment proposed by the health care providers; or when we have reached the limits of what we can offer medically, then the decision can only be based on what is ethically appropriate. However, principle-based ethics is somewhat problematic because it is not unusual for there to be conflicts if one principle is chosen over another, or if the rights of one person supersede those of another.

An example of this potential conflict was described by Nancy Case: "Absolute parental autonomy might lead to unnecessary pain, suffering, and even death in cases in which parents were either unable or unwilling to make a decision in the best interests of their child. Absolute health care professionals' rights may overlook the needs of the child's family. . . . this absolute position promotes and sustains a paternalistic attitude. . . ." She concludes that "The rights of parents to decide for their children must be balanced against the rights of health care professionals to seek the health and well-being of those entrusted to their care."<sup>2</sup> If indeed all things must be considered, then principles other than autonomy, such as beneficence, non-maleficence and justice cannot be ignored. Choices are bound to be more difficult if resources are limited. And if there is disagreement about what will benefit a patient, then deciding on the best course of action will be tricky. The various people involved, and their personal or professional moral values, must also be taken into account. For instance, it might be difficult to withdraw life support if one's value system were based on the sanctity of life, and quality-of-life issues were important in the value system of other stakeholders involved in the decision. In a case of conflicting values, whose values take precedence? A shared decision making model, one which balances caring and justice and deals with issues in the context in which they occur, might be more helpful in resolving ethical dilemmas surrounding the care of children who lack decisional capacity, specifically neonates.<sup>3</sup> One example of such a model is rela-

tional ethics, in which interaction with the patient and family increases the likelihood of recognizing the complexities of the situation and identifying a broader range of possible options, thus making dialogue more inclusive.<sup>4</sup>

## Involving the Parents in the Decision Making Process

If our goal were to determine optimal care—what is appropriate in a particular situation for a particular patient and family—rather than maximal care possible, the information we share with the family would be quite different. ". . . [T]o a large extent parents' best-interests determinations in the NICU setting are shaped by their understanding of medical information and the recommendations of their infants' caregivers."<sup>5</sup> We seem to be imposing on parents our assumptions about what they want for the care of their sick children, by not asking what they want, by asking selective questions, or by not sufficiently valuing important information they share with us. Health care professionals also share

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information selectively with parents. I do not mean to imply that information is intentionally withheld from parents, but it is often done with the desire to protect parents from our own fears and misgivings. The transparency model of informed consent proposed by Howard Brody has been modified somewhat for neonatal intensive care by Nancy King. In the case of neonates, uncertain prognosis can be a major difficulty in planning care, and one of the challenges for health care providers is to prepare the parents to participate in decision making with awareness of this uncertainty. This is particularly true when there is increased potential for mental or neurologic deficits, secondary to prematurity or other severe illness in the neonatal period. It is difficult to predict the ultimate severity of the deficit and specifically what functions will be affected. We can better prepare parents for facing this unknown future by sharing not only technical information with them, but also the meaning and implications of this information as perceived by the health care providers, based on their knowledge and experi-

ence. This gives parents an opportunity to better understand the recommendations for treatment. It also provides for improved informed consent so that parents can take advantage of this expertise and be adequately prepared either to assent to or dissent from these recommendations. This may prevent disagreements based on misunderstanding rather than on different values.

Despite the need parents have for information, they focus primarily on the care their child receives, rather than on issues of rights or justice. They do not seek completely autonomous decision making authority, but recognize their dependence on health care professionals to guide them. They seem to desire shared decision making.<sup>6</sup> This is not an appeal

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to return to the paternalism of the past, but an attempt to reach a decision whereby all involved parties will work toward the best outcome for the child. This goal can be realized by recognizing the importance of the relationships among individuals in providing health care and in making treatment decisions, rather than trying to choose one or more persons who will have ultimate decision making authority.

The parents' voice needs to be amplified in ethical decision making for infants. It is important to involve the parents as early and as completely as possible in decision making. Just as parents need the medical and technical information we can offer to determine the best outcome for their child, we in turn need the values information only they can offer. It is also important to acknowledge the legitimate role of emotion in ethical analysis.<sup>7</sup> We must explore with the family their values and experiences and how these influence their perceptions and decisions in a particular situation. Parents know details about the family's life, they know how the child "fits" into the family; for instance, previous losses or experience with another seriously ill child may influence how parents make decisions.

It might be useful to share our values and experiences with the parents as well (the idea of transparency carried a bit further). If a trusting relationship has developed, parents often find comfort in hear-

ing stories of how other parents in a similar position have dealt with their circumstances. Parents might also benefit from our viewpoint as health care professionals in caring for a child with an uncertain outcome. It is also important to identify any cultural or religious beliefs and practices that may shape decisions about health care or life and death issues. This information should be incorporated into the care plan for the infant and shared with other members of the health care team.

Clear and adequate communication with the parents is essential, particularly about the implications of the infant's condition. For example, "Your baby is very sick" may mean to the nurse or doctor that the baby might die, but a parent may interpret this to mean the baby will need to be in the hospital longer than they anticipated.<sup>8</sup> Improved communication should eliminate disagreements caused by misunderstanding. Consistent communication by various practitioners and consultants also enhances parents' understanding. It is important to keep parents up to date because as conditions change treatment may also change. This could be accomplished by periodically assessing parents' understanding of the situation, identifying information needs, and assisting parents to articulate their desires to the health care team.<sup>9</sup> Encouraging open communication among family members so that they can understand each other's perspectives may help them to speak with one voice. In some cases it may be appropriate to involve other family members besides the parents. Although including parents in decision making is time-consuming and draining for members of the health care team, this will likely improve the chances of an outcome everyone can accept. "From a pragmatic viewpoint, it is difficult to imagine that parents can adapt well to the lifelong responsibility for an impaired child if they have been excluded from crucial treatment decisions early in the child's life."<sup>10</sup> Caring for a child who may never function independently, who will need care by a family member or in an institutional setting, may require reordering personal or family goals. Often what requires the most thoughtful reflection is not so much what to do, but, once the decision is made, what it will mean for the future of everyone in the family, including this newest member.

### **Additional Voices: Nurses and Other Health Care Providers**

Having said all this, it is important to recognize that the parents' voice is not the only valid viewpoint in such decisions. Although the relationships between health care professionals and their infant patients differ in character from the relationships

between parents and their children, these relationships should not be ignored. Because of their unique perspective in the health care team, nurses must add their voices to the discussion, both as patient and family advocates. Nurses know their patients! Nurses often have intimate relationships with the patients and families they care for, and parents often share information of a more personal nature with nurses than they do with physicians. In addition to the technical expertise required, the nurse also functions to link cure and care. How? By helping to meet the human needs of those who suffer from disease or disability, by assessing the individual's response to illness and treatment, and by intervening through communication and education. I feel that an important element of nursing that enhances this sharing of information is the time spent building a relationship with the patient and his or her family; learning the meaning of what is said, not just the words; and developing trust. Nurses may also have relationships with physicians that allow them to convey their impressions of parental coping skills and understanding of information. Nurses can also invite questions that parents may be uncomfortable asking the physician. Additionally, nurses may be the most available health care professionals for family members when information needs to be shared in either direction.

With changes in how health care is delivered, and the loss of long-term physician/patient/parent relationships, it is likely that the health care providers will at first be total strangers to the family of a sick newborn, and nurses will need to compensate for inconsistencies in medical care that may occur. Because parents may have little choice but to trust the judgment of health care providers, this increases our obligation to communicate clearly about the medical facts and what these mean for the child. We cannot abandon parents to make medical treatment decisions for their children unassisted. They will need the support, empathy, and patience of the nurses and physicians caring for their child.

Situations are sure to occur in which health care providers believe parents have made a poorly reasoned decision for their child, despite good communication. In my experience, the initial response is an attempt to identify and correct any misperceptions or miscommunications. It is often useful to draw on other people who have developed a relationship with the parents, such as a social worker, a chaplain or other family members. It is important to keep in mind that previously intact decision making abilities can be compromised after a traumatic event such as the birth of a severely ill or damaged baby. Sometimes what is needed is more time—for the parents to deal with their feelings about possible

options; for them to recognize things they may have been denying about their child's condition or prognosis; for discussion with each other or other family members in an effort to reach agreement about any decision. What may be required is a determination of parental competency with regard to decision making, "assessing the parents' ability to obtain and understand information necessary for a decision, to demonstrate a capacity for decision making, to act voluntarily, and to possess an ability to separate their own well-being from that of their child."<sup>11</sup> However, if reasonable efforts fail, other means of conflict resolution are needed. Alternatives might

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include: (1) consulting with another physician for an independent opinion; (2) involving a trusted family advisor to help clarify issues and values; (3) consulting a multidisciplinary ethics committee; (4) involving state or county social services; and (5) court involvement, as a last resort. Courts should be an alternative of last resort because they are required to look primarily at the legal issues, regardless of whether the outcome is ethical or not. Moreover, it is difficult for the courts to consider the consequences only as they apply to the individuals involved.

The use of an ethics committee may not be ideal, as it may not be aware of or sensitive to the relationships of all the people involved. However, if all other efforts have failed, the ethics committee may be able to suggest new alternatives more acceptable to everyone. "Complex ethical decisions cannot and should not be codified into legislation, and a physician's responsibility to his patient cannot be abrogated by delegation to a committee."<sup>12</sup> I would add that the nurse cannot deny his or her responsibility in this regard either. If an ethics committee is consulted, it needs to be with the understanding that its role is to review the decision making process and clarify options, rather than to participate as a decision maker.

Examining one's own values will further enhance the ability to discuss difficult ethical issues with parents. By exploring those clinical situations that

have caused us the most difficulty and discomfort, nurses can identify what makes them challenging and better recognize similar situations when they occur. If this exploration is grounded in basic values important to us, we can be more sure of our responses rather than just reacting to the discomfort and possibly withdrawing from the situation. This self-reflection will hopefully have the additional benefit of allowing us to recognize different values held by others and appreciate the impact of these values on the decision making process. This more empathetic viewpoint may lead nurses to act as advocates for the patients they care for, and for the parents of these children as well.

### The Decision Making Partnership

A study of advocacy behavior on the part of neonatal nurses revealed that with increased certainty of outcome, either positive or negative, nursing staff had little conflict with treatment or nontreatment decisions if they were justified by the prognosis. "The ethical anguish. . . occurred when nurses felt that infants suffered for no justifiable reason."<sup>13</sup> Primary nursing may lead to increased advocacy for the patient by nursing staff. Sustained interaction with a specific infant leads to better recognition of responses to treatment, or lack thereof. Primary nursing can also lead to more consistent communication with parents and the health care team. Treating the patient as part of a family, as well as an individual, will help the family to be more involved in their child's care, and this in turn will increase their awareness of the special care their child receives from the nurses. Attention in care plans to inclusion of parents may also facilitate advocacy behavior on the part of neonatal nurses. It is important to remember that parents will pay attention to things that we pay attention to. For instance, if the only information we share with parents is lab results or monitor readings, that is what the parent will ask about when they call or visit the NICU. Sometimes we need to point out the baby amid the technology, and to remember to share with the parents what is normal about their baby as well as what is not normal. Nurses can point out to parents their infant's behaviors, and how we interpret them as positive or negative responses to interventions or stimulation. The importance of encouraging parents to recognize the infant's signs of response to treatment, rather than relying only on monitor readings or lab results as indicators of response, cannot be overemphasized. We can role-model advocacy behavior for parents. In an environment where parents often feel helpless and unable to contribute to their child's well-being, this can facilitate bonding

and thereby increase parents' sense of responsibility for their baby.

As stated in the ANA *Code for Nurses*, "The interdependent relationship of the nursing and medical professions requires collaboration around the need of the client."<sup>14</sup> Clear communication among professionals is critically important. However, this is not to say we will always agree with each other. Nurses must be willing to share their insights, or any pertinent information they obtain in their intimate relationships with the families of sick children, with other members of the health care team. When there are many specialists involved in a particular case, the open sharing of all relevant information can avoid misunderstanding caused by inadequate or incorrect information. Education for health care providers about ethical decision making and conflict resolution would also foster collaborative relationships.

In the broader community, there are many ways in which nurses can improve the ethical decision making process. Increased nursing involvement in

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the debate over health care reform, and in creating solutions to the problems discussed here, will benefit nurses and their patients by empowering nurses and encouraging them to advocate for their voiceless patients. Nurses also have a role in developing institutional policies that have implications for ethical decision making. A more accurate representation to the public of what we can and cannot do—discussing our failures as well as successes—would go far toward eliminating some of the unrealistic expectations about what we are able to accomplish, and hopefully avoid some of the conflicts that occur because a perfect outcome is expected in all cases.

When difficult decisions must be made in the NICU, we would all like to ensure that the best possible decision will actually be made. By acknowledging the moral significance of relationships in health care, and pediatrics in particular, nurses and other health professionals can provide care that is more sensitive to the values of the families we touch in our practice. At the same time we will be able to maintain the ethical integrity which allows us to continue to care for critically ill newborns and

their families, despite the pain we inevitably feel, and sometimes cause.

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