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# Moral Distress — the Role of Ethics Consultation in the NICU

By Lucia Wocial

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*Moral distress is a common occurrence for individuals involved in the care of critically ill infants. The ability to reason through difficult situations is often complicated by intensely emotional circumstances. Ethics consultation in the Neonatal Intensive Care Unit is a useful tool for caregivers and families who face moral problems. Understanding the responsibility of caregivers and parents to act as independent moral agents is an essential element in reducing moral distress and working collaboratively to resolve moral problems.*

Consider the following scenario: a term gestation baby girl is delivered by cesarean section because of prior maternal cesarean sections and a prenatal diagnosis of a lethal congenital anomaly. The parents decide they do not want aggressive interventions when the baby is delivered; in fact, they do not expect the baby to survive.

At delivery, the baby is in no distress. The attending physician admits the baby to the Neonatal Intensive Care Unit (NICU) for routine care, including heel sticks to monitor blood glucose levels, tube feedings or intravenous fluids to maintain a normal blood glucose, cardiopulmonary monitoring, and — absent an explicit order otherwise — full resuscitation. At the time of admission, there is no formal discussion about the plan of care, other than to treat the baby as other babies in the unit are treated.

Several tests to confirm the diagnosis are scheduled. The baby's physical examination is consistent with the prenatal diagnosis. The mother is moved to the post partum unit, down the hall from the NICU.

Before continuing this article, consider the issues presented by this birth, which is a paradigm for understanding moral distress: If this were your baby, what would you want in her plan of care? What would you consider a good death for a

baby? How, and when would you discuss end-of-life care with a baby's parents? What would you say to convince them that your approach is in the baby's best interest?

In this realistic, though hypothetical case, parents have come to the hospital prepared for the death of their baby girl, only to have her survive and be in no real distress. The attending physician appears to be ignoring the nature of the baby's condition by treating her as a routine admission. The nurses caring for the baby are distressed: they believe that the baby may suffer a life threatening event that will require them to initiate resuscitative efforts inconsistent with the parents' wishes. Nurses caring for the mother must help both parents cope with the unexpected outcome of the delivery.

Since the baby is not in immediate distress, she is caught in the "routine" of medical care that can prolong her life, but not correct her underlying problems. If she does not die in the hospital, her parents will have to face issues of hydration and nutrition at home. Everyone involved in the baby's care has a role to play and strong feelings about how the care plan should be made and when it should be discussed. In this article I will examine the role of an ethics consultation in alleviating the emotional and moral distress that often accompanies work in the NICU.

## **An Intimate Affair**

So often in the literature, ethics is debated in the context of rights, principles, and theories. For those involved in patient care, however, ethics is a personal, intimate affair. Ethics involves not only understanding principles and respecting rights, but reasoning through deep emotions such as fear, anger, grief, gratitude, pride, embarrassment, and love (Elliot 1992). Uncomfortable and intense emotions are often the first sign of moral distress.

Policy and law set boundaries for human behavior (Elliott 1992). Emotions, however, know no bounds. In describing a given case, some of the ethical work is already done in the presentation of information. Keep in mind, however, the gulf that can develop between moral description and moral experience. No description can ever be completely objective. No short case presentation can ever do justice to the intense emotions and depth of detail experienced by those involved in the case.

## **The Role of Emotion and Reason**

Callahan (1988) defines emotion as “distinctly patterned human experiences that when consciously felt, produce qualitatively distinct subjective feelings and predispositions” (p. 10). Emotion is what motivates people to enter into ethical discussion. Having emotions means that a person is interested enough to risk personal integrity in pursuit of doing what he or she feels is best. Unrestrained emotion does not contribute to a constructive discussion or resolution of a problem.

An emotionally grounded resolution to moral problems occurs when reason, in the guise of a model or framework, is used to focus one’s emotions on the facts of the case. Being reasonable is about staying focused. It requires clarity about one’s own principles and values, sensitivity to one’s own feelings, and an examination of their significance. An ethics consultation is an ideal mechanism for focusing emotions by generating reasonable discussion.

## **Triggers for Consultation**

Three circumstances trigger the desire for an ethics consultation: moral dilemmas, moral uncertainty, and moral distress. Moral dilemmas result when at

least two clear moral principles apply to a case, but support mutually inconsistent courses of action; or when information suggests that an act  $x$  is both right and wrong, or the evidence is inconclusive, or a person believes on moral grounds that one both ought and ought not perform  $x$  (Buchanan and Brock 1989). Formal consultation by an ethics consultation service or committee is called for in these circumstances.

Moral uncertainty results when one is uncertain about what principles or values apply, or even if one really has a moral problem (Jameton 1984), or when individuals feel that something is not quite right, but need assistance in pinpointing what that something is. In circumstances involving moral uncertainty, discussion with colleagues and peers may be a useful way of determining clarity. It is not uncommon for moral distress to surface once uncertainties have been clarified.

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Moral distress follows when persons know the right thing to do, but something or someone restricts their ability to pursue the right course of action, or they perceive that such is the case. Moral distress arises from deeply felt emotions. Direct distress occurs when one detects a conflict in values, or perceives a barrier to acting on one’s feelings. Should an individual fail to act on this initial distress, he or she may also suffer reactive distress. Moral distress raises questions about individual responsibility more than questions of principles or values (Jameton 1994).

Individual moral agency and integrity are central to handling moral distress. One is obligated to help others, in this case, the baby girl and her

family (direct distress). One is also obligated to be true to oneself (reactive distress). An ethics consultation will not resolve moral distress, which continues even after a decision has been reached and actions taken. The process of consultation will often diminish one's moral distress.

### Using an Ethics Consultation Service

The following discussion is modeled on the service used by the Mayo Clinic in Rochester, Minnesota.

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Knowledge of its goals, composition, and consulting methods can help us understand the role of such services in helping individuals handle moral distress.

The patient-focused goals of an ethics consultation service are to promote an ethical resolution to the problem at hand, establish comfortable and respectful communication among involved parties, and help concerned individuals work through ethical uncertainty and disagreement on their own by illuminating issues (Andre 1997). In general, decisions or recommendations of consultations are advisory and not binding.

A well-balanced consultation service team includes representatives from medical staff, nursing, social services, chaplain services, legal counsel, administration, and other disciplines. Members of the team must receive special training in ethics consultation and be able to demonstrate competency in performing ethics consultation (ASBH 1998). Members of a consultation service need to have an ability to listen carefully, a willingness to hear and respect other voices, and a readiness to reveal their own values.

Consultations may be formal, in which case the team will gather to facilitate discussion about a dilemma; or informal, in which case a single member of the service will provide feedback to individuals seeking the team's assistance. The ideal formal consultation will have at least one physician and one nurse among its members, and in many situations, it is prudent to seek legal council.

Formal consultations offer more than assistance with resolving dilemmas. They provide opportunities for education and an immunization against future problems by fostering an open environment for discussion. However, the resources and culture at many institutions may limit or preclude formal consultations in cases involving moral distress, but no clear conflict.

Informal consultations offer other benefits. An informal consultation does not imply a disorganized discussion about the issue at hand. It provides for one-on-one interaction with a member of the consultation service and an opportunity for the institution to demonstrate that it has resources available to help individuals think through their distress. Exposure to this resource may lead to constructive discussion about educational needs and generate ideas for how to meet those needs. Whether formal or informal, the contribution made by the consultation to the patient's plan of care should be documented.

### Initiating the Consultation

The Joint Commission for Accreditation of Health Care Organizations (JCAHO), itself a multidisciplinary group of agencies, accredits healthcare organizations as a way to insure high-quality patient care. JCAHO has also set standards and guidelines for addressing ethical issues in providing patient care (JCAHO 2000). According to the standards, organizations must establish and maintain structures to support a patient and his or her family's right to participate in ethical discussions related to patient care. Ideally, an ethics consultation will be requested by a member of the healthcare team directly involved in the patient's care, or by the patient, his family, or surrogate.

A consultation service must be available any time. An effective method for maintaining twenty-four-hour availability is to have members on call on a rotational basis. They should be reachable by pager at all times when they are on call. At the Mayo clinic, a published mechanism for reaching the on-call member of the service assures its availability to healthcare professionals, patients, and their families.

If someone other than the patient requests a consultation, the principles of respectful communication require that the consulting member notify the patient or the patient's family or surrogate. If someone other than the attending physician requests the consultation, the requester should be encouraged to notify the attending physician. If the requester does not feel able to notify the physician directly, the consultant should do it. When a formal request for consultation is made, every effort should be made to meet the request within twenty-four to forty-eight hours.

### **The Process of the Ethics Consultation**

Steps in the decision-making process typically include defining the issues, identifying goals and values, gathering information, deliberating, making the decision or recommendation, and evaluating the process. If the facts are organized to define the issue, involved parties will be free to express their concerns and clarify their own and others' legitimate positions. The process will not only achieve compromise and address moral distress; it should also yield a decision that can withstand the scrutiny of later review.

The first stage in the process occurs when the consultant on call determines that the request is appropriate. However, it may not be readily apparent whether the need is for a formal or informal consultation. He or she must determine how to proceed, taking into consideration from whom the request was received, the nature of the request, the risks involved for interested parties, and the goal of the consultation. If, while reading the patient's chart or during interviews with key individuals in the patient's care (including the patient or surrogate), the consultant identifies the need for formal consultation, a meeting should be scheduled.

In our opening scenario, the most pressing issue for the baby's caregivers is to determine appropriate end-of-life care for the baby and her family. Embedded in this central issue are principles of doing good, avoiding harm, keeping promises, respecting and trusting each other, and futility. Values to consider include integrity, advocacy, and collaboration. These principles and values are emotionally charged, especially as they affect the life or death of a baby. A well thought-out model for organizing the facts is essential for gathering information and rationally focusing the parties' powerful emotions. The model described by Jonsen, Siegler, and Winslade (1998, 1986) is one such tool. This model uses four categories, medical indications for treatment, patient preferences, quality of life issues, and context, to organize information pertinent to the discussion.

### **Medical Indications**

Medical indications for treatment include an examination of the features of the illness and clinical goals. Table 1 summarizes Jonsen, Siegler and Winslade's discussion of medical indications (1998,

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1986), for which it is appropriate to discuss treatment limitations. In pediatrics, however, medical indications almost always dictate full treatment, at least initially. There are powerful reasons why this approach is standard.

First, prognostic uncertainty is an inescapable reality in determining medical indications for treatment. Prognostic uncertainty guarantees that, at times, predictions about morbidity or mortality will be wrong. Opting for treatment allows the possibility that the life preserved will be worth living. It is morally distressing to contemplate the end of

**Table 1. — Indications for Medical Treatment**

Indication	Features	Clinical Goals	Ethical Problems
<i>A CURE</i>	<ul style="list-style-type: none"> <li>• Acute</li> <li>• Critical*</li> <li>• Unexpected</li> <li>• Responsive</li> <li>• Easily diagnosed and treated</li> </ul> <p>*Life threatening</p>	<ul style="list-style-type: none"> <li>• Cure disease</li> <li>• Save life</li> <li>• Preserve function</li> <li>• Relieve pain</li> <li>• Restore function</li> </ul>	<ul style="list-style-type: none"> <li>• Refusal of treatment</li> <li>• Parents disagree about treatment options</li> <li>• Unavailable resources (limited beds)</li> </ul>
<i>CARE</i>	<ul style="list-style-type: none"> <li>• Critical*</li> <li>• Active</li> <li>• Recalcitrant</li> <li>• Eventual</li> </ul> <p>*Critical may be acute exacerbation of a chronic disease</p>	<ul style="list-style-type: none"> <li>• Prolongation of life</li> <li>• Relief of pain</li> <li>• Maximal preservation of minimal function</li> <li>• Enhancement of dignity and control</li> </ul>	<ul style="list-style-type: none"> <li>• Withdrawing life support</li> <li>• DNR/DNI</li> <li>• Limiting aggressive treatment</li> </ul>
<i>COPE</i>	<ul style="list-style-type: none"> <li>• Chronic</li> <li>• Outpatient</li> <li>• Palliative</li> <li>• Efficacious</li> </ul>	<ul style="list-style-type: none"> <li>• Minimize need for future medical intervention</li> <li>• Optimize independence, function and quality of life</li> <li>• Preserve life</li> <li>• Relieve pain</li> <li>• Educate and counsel</li> </ul>	<ul style="list-style-type: none"> <li>• Noncompliant patient</li> <li>• problem patient</li> </ul>

Note: The bulleted points under “features” explain the acronyms in the “indication” column (table based on discussion in Jonsen, Siegler, and Winslade [1998, 1986]).

life when life is just beginning, and support for the “treat until we know more” approach is extensive because it addresses the immediate best interests of the newborn: surviving. This approach deserves closer scrutiny, however, because it may compromise consideration of the infant’s long-term best interest: thriving.

Second, in pediatric cases, uncertainty is often compounded because children, especially babies,

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have an amazing capacity for recovery. The outcome of a proposed treatment for a particular patient always depends on the circumstances of person, place, time, and culture (Jecker and Pagon 1995). Restoring an infant to a “healthy” state may be deceptive, but how deceptive may not be known for years. This reality, combined with a tendency to protect parents from unnecessary burdens during initial diagnosis and treatment, also leads to a default to treatment, as happened in our hypothetical example.

Their newborn infant was essentially everything her parents dreamed she would be. The future becomes a limitless possibility in their imagination. When she didn’t die as expected, the initial diagnosis is doubted, and their hope, whether false or not, is that somehow, it will turn out differently.

Routine interventions at the time of unexpected survival make shifting the focus of care to compas-

sionate support even more challenging. Timing is important, and efforts to protect ourselves or the parents by delaying difficult discussions while tests continue is a recipe for escalating moral distress. We must also recognize that moral distress will not go away no matter what the outcome.

#### *Patient Preferences*

Treatment decisions deal largely with physicians’ judgments. Patient preferences in the case of newborn infants are more accurately described as parent preferences. Honoring parent preferences depends on timely discussions early in the treatment process. Healthcare providers must determine the parents’ capacity to make decisions, their ability to provide informed consent, and to decide what is in their newborn’s best interest.

Capacity is basically the ability to understand and communicate information, ability to reason, and the ability to choose in light of values and goals (Buchanan and Brock 1989). A note of caution: preferences for alternative medicine, refusing treatment, and unfamiliar cultural practices are not uncommon and need to be investigated carefully before jumping to conclusions about capacity.

The usual means of determining parent preferences is the process of informed consent (Jonsen, Siegler, and Winslade 1998). Ideally this process includes a discussion between physicians and

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parents, not simply an explanation of the benefits, burdens, and alternatives of the various treatment options. Informed consent depends on communication that is open to interpretation. Uncertainty about whether the parents have given truly informed consent is a potential source of moral distress for caregivers who were not directly involved

in the process but are nevertheless charged to carry out the decisions reached in the discussion.

Best interest is perhaps the most contentious concept in pediatrics. Best interest expresses a positive obligation: a duty to do what best promotes someone's interests (Buchanan and Brock 1989). At different periods in history, and within different cultures, the perception of a child's best interest has varied (Lansdown 2000). Treating the best interest principle as an absolute commandment imposes morally impossible demands on decision makers; persons other than the parents also have legitimate interests in this determination (Buchanan and Brock 1989).

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982) issued a report that has had a strong impact on how the best interests standard is determined for critically ill newborns. One of the most troubling and persistent issues in pediatrics is whether, or to what extent, the expectation of handicaps and other limiting conditions should be considered in deciding to treat or not to treat seriously ill newborns and children. The commission recommended a standard whereby permanent handicaps justify a decision not to provide life-sustaining treatment only when conditions are so severe that continued existence would not be a net benefit.

Members of the commission believed that a strict standard should be used in uncertain cases. The standard excludes consideration of the negative effects of an impaired infant's life on other persons, including parents, siblings, and society. They chose this standard over recommendations for considering the best interests of adults because they were concerned that the lives of handicapped infants would be undervalued. Because the best interests standard is subjective, it tends to be paternalistic.

However, the commission's guide places a great burden on physicians because it places a significant weight on indications for medical treatment and judgments of futility. In effect, it delegates the power to define the best interests of the infant

to the physician. Given that medical judgment is colored by the values of the individual making the judgment, and that parents must live with the long-term consequences of the decision, placing the greatest burden for determining best interests

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on physicians is perhaps ill advised.

As children exist within the context of their families, it is crucial to consider the family as part of the best interest of individual children. A contextual definition of best interests is more likely to provide reasonable results for all affected persons. This definition is perhaps vague, but it allows more weight to be given to the values and preferences of those who will be intimately involved in the baby's care, not only while she is in the hospital but throughout her entire life. In most instances, families are more than willing to care for their children, even at great cost to the family in time, money, and emotional energy.

### *Quality of Life*

Quality of life is multidimensional. It is a value statement of subjective satisfaction. Quality of life assessments change over time. In assessing quality of life for critically ill newborns, an intrapersonal rather than a comparative value assessment is most appropriate. Newborns are not capable of communicating their quality of life beliefs. Since children most often reflect the values of their parents, the parents of newborns should be involved in assigning a value to the quality of life their newborn can expect given the probable medical complications and cares neces-

sary to sustain life.

One source of moral distress for caregivers of critically ill newborns is the knowledge that limited resources are available to families who have children with special needs, especially those who are medically fragile. It is not uncommon for babies to be discharged home with supplemental tube feedings, supplemental oxygen, and a bevy of

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monitoring and emergency equipment. The babies are discharged because they are medically stable, and their nursing care is routine for highly trained nurses. Caring for a baby with these needs in the home is far from routine for families. It is hard for hospital caregivers to celebrate the survival of a baby to discharge only to worry about the impact her life will have on her family.

### **Context**

The fourth aspect of this model is a consideration of contextual features. The details of special circumstances must be known to appreciate other facts in the case. Exploring confidentiality and the legal, financial, social, spiritual, and cultural resources of the family is central to a reasoned discussion of issues involving moral distress and conflict. Contextual features challenge our sense of individual moral agency. We may be able to set aside our personal values once we appreciate the context of individual patients.

### **Developing Self-Awareness**

Having organized the facts of a case, the next challenge is to bring emotions into focus and deliberate reasonably to achieve a collaborative consensus about the best course of action. Each participant in the discussion has a personal responsibility to exercise his or her moral agency. Moral agency

is the capacity for voluntary, purposeful actions, which one recognizes as influencing the well-being of others. The exercise of moral agency depends on understanding oneself as a causal agent, and understanding the moral values and principles at stake in a discussion (Brody Mahowald 1993). In short, it is about developing self-awareness.

Developing self-awareness requires rigorous honesty, genuine humility, and a willingness to consider the opinions of others. Constant contact with suffering, especially in the care of critically ill newborns can overwhelm and even paralyze a compassionate healthcare worker (Lansdown 2000). It may also cause some of them to form opinions about what is in the newborn's best interest earlier than others, including the parents. A firm sense of one's own boundaries is necessary for coping with moral distress and defining one's sense of moral agency. Being open to and seeking an ethics consultation is a way to develop integrity, which is, in part, a quest of the self in conversation with others (Winslow and Winslow 1991).

Moral distress is disruptive to organized thoughts and can disturb individual moral agency. It is not enough to claim moral distress. Being able to describe it, discuss it, and articulate the moral basis of the distress is one way individuals can influence the well-being of others. Being able to clearly express the complexities of moral distress requires reflection and practice. Participation in ethics consultation is an opportunity to practice this skill.

Healthcare professionals are challenged to explore within themselves the boundaries of their ability to accommodate values and commitments that are different from their own (Rushton 1997). Participating in informal or formal ethics consultations is a purposeful action that fosters the exercise of individual moral agency. Participation may mean getting feelings hurt because the emotions that motivate you to participate are very personal. Courage to exercise moral agency, and sufficient compassion and caring will not inoculate one against situations that appear to require one to compromise his or her integrity. The limits of compromise are reached when we feel certain



that a particular course of action is right and compromise on that point would mean losing that which is central to our sense of ourselves as moral agents (Winslow and Winslow 1991).

## Conclusion

Reasoned discussion in the form of ethics consultation is a tool and should not be used to protect us from the changes and biases of our emotions. Participating in ethics consultations, formal and informal helps develop the skills to deal with direct and reactive moral distress. It is not uncommon to experience a change of moral intuitions during a consult. Moral intuition is part of integrity, which is nurtured as individuals learn from experience.

The following exercise can help one apply the ideas and arguments presented in this article. They relate to our fictitious case and pose questions modeled after exercises from Beck Kritek (1994). First, identify, in writing, the emotions you experience as you reflect on this case. Identify in your own words the circumstances that may lead to moral distress, the issues you feel need to be discussed, and the outcome you hope for.

Second, imagine yourself as another individual involved in this case with a different role. Consider how that person's role might affect his or her sense of the issues and outcomes. Third, compare the differences between you and the other person. Identify the advantages each one has depending on how he or she is involved in the case. Do these advantages make a difference in the outcome of the discussion? Why? How does that relate to the original issue? Were issues of personal integrity involved? How is one's personal integrity maintained in this case? Would it make a difference for the baby and her family? Would it make a difference for you?

Performing the same exercise on an actual case can help caregivers recognize that they have a positive role to play. We learn from our failures, certainly, but we gain strength the more we nurture and celebrate our success.

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