

## CENTER NOTES

I am pleased to introduce Alan Lubert as the new editor of *Midwest Medical Ethics*. Alan recently received his Ph.D. in philosophy from the University of Rochester in New York; however, for some time he has been a Kansas City resident. Alan has taught philosophy at Rockhurst College, Avila College and Central Missouri State University. In addition, he has been very involved in community activities. We are pleased to have Alan join our staff, and we are confident that under his direction *Midwest Medical Ethics* will continue to provide timely, pertinent information to our readership as it has under the direction of our former editor, Karen Ritchie, M.D., M.A.

This spring, Karen resigned as editor. Karen is one of the founders of Midwest Bioethics Center, was the first president of the Center, and has been the editor of this publication since its beginning. Karen continues to serve as a board member and has decided to pursue her doctorate at the Kennedy Institute at Georgetown University. All of us associated with the Center wish Karen well and would like to express our gratitude to her for her contribution to the Center—without her vision and dedication there would be no Midwest Bioethics Center.

In June, Shawnee Mission Medical Center and Midwest Bioethics cosponsored the First Annual D.K. Breyfogle Conference on Gerontology. Shawnee Mission Medical Center graciously allowed the Center to take the profits generated by the conference to support the cost of this publication. I wish to thank Shawnee Mission Medical Center for their ongoing and generous support of our work.

Myra J. Christopher  
Executive Director

## Decisions Concerning Imperiled Newborns: What Should Be the Parents' Role?

by Don Marquis

### 1. Introduction

A recent issue of *Hastings Center Report* was devoted largely to the ethics of treating imperiled newborns. One section of that issue was concerned with who should decide when treatment decisions must be made in the newborn intensive care unit (NICU). It said:

[Ethical considerations] point in the direction of parents as most likely to make loving and concerned decisions regarding the best interests of helpless and dependent infants. Also, they support placing decision making entirely within the realm of parental discretion when only the relational potential standard can apply. Further, they suggest that review of parental decisions should be available when parents make decisions that may not be in the best interests of their children.

[*Hastings Center Report* 17 (December 1987) 17]

Although this endorsement of parental decision making in the NICU is neither unqualified nor clear, plainly the authors intended to emphasize parental decision making in the NICU. It is not clear how this view of decision making fits in with the legal and medical realities of the NICU. Further, one wonders how this view of decision making can be compatible with plainly defensible ethical imperatives that apply to newborns. The purpose of this essay is to explore these issues.

### 2. Representing the Interests of the Newborn

What kinds of decisions are made in an NICU? Infants in the NICU are newborns who require more intensive care than can be provided in a normal hospital nursery or at home. Some of these infants are premature

and need to be supported by artificial means until they mature. Some of them are full term infants who have some life-threatening problem such as infection or difficulty breathing and who require treatment and support of the vital functions. Still others are born with an anomaly that requires surgical correction. They need close observation and treatment both before and after surgery. All of these infants require careful medical management based on data obtained from close physiological monitoring.

On the face of it such medical management decisions should be made by pediatricians specially trained in neonatal medicine for the very simple reason that such physicians are best qualified to make them. There is nothing odd about this judgment. We assign decision making responsibility to experts in many relatively technical fields because wise decisions require expert knowledge. Lay people, even parents, are unqualified to make these decisions.

This quick analysis suggests a case for a "doctor knows best" model of decision mak-

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ing that has been rejected in most of the literature in contemporary medical ethics. Let us examine whether the usual reasons that can be offered for rejecting the "doctor knows best" model apply to the NICU.

A standard view in contemporary medical ethics is that, although medical decisions often require the expertise of a physician, they involve other components, implications, and values as well, and that because of these other components the participation of the patient and his or her family in decision making is morally required. Surely, as a general proposition, this doctrine in contemporary medical ethics is correct.

What are the implications of this doctrine for medical situations found in the NICU? In general, there are all sorts of good reasons for getting informed consent from a patient prior to an invasive medical procedure even when the recommendation to perform that procedure is based on the considered medical judgment of a specialist. But this general proposition doesn't apply in the NICU since the patients there are not capable of giving informed consent. The standard doctrine of informed consent is a doctrine for competent adults.

Often when a patient is incapable of giving informed consent, the patient's family is asked to give proxy consent on behalf of the patient. Should this doctrine apply in the NICU? The answer to this question is determined by the correct account of why that proxy should be given to the family rather than to someone else (such as the physician). One gives the proxy to the family in many medical situations because a patient's family best knows a patient's values and sentiments and, therefore, is in the best position to know the judgment the patient would have made if he or she were able to make it. However, this rationale, which is defensible in the case of adults, and especially in the case of adults with relatively long life careers, has no application at all in the case of infants, for they have never developed values and sentiments.

Consider another strategy for defending parental decision making in the NICU. Since families typically make decisions for older pediatric patients, perhaps the justification for such parental decision making might also apply to the NICU. Why is it important that parents participate in medical decision making on behalf of children in ordinary pediatric contexts? Medical judgments concerning school age children surely should take into account the fact that a child has a life apart from medicine. Accordingly, a child's schooling and social life properly should affect the pace or scheduling or nature of medical interventions on that child. Parents will usually be better acquainted with these matters than physicians.

However, these considerations are almost irrelevant in the NICU. Newborns do not go to school. Newborns do not interact with

their peers. Medical decision making clearly needs to be integrated into the nonbiological aspects of the life of a child or an adult; however, the nonbiological aspects of the life of a newborn are almost nonexistent. Granted newborns should be touched and cuddled if that does not interfere with their medical care. Parents are encouraged to do that in the NICU. However, this does not seem to entail giving parents a larger decision making role.

There is a way of thinking about the NICU which supports this emphasis on the biological. Some infants who are expelled (often prematurely) from their uterine environments are not yet prepared to be as biologically independent as normal infants. The NICU functions as a surrogate uterus for such babies. The point of uterine existence is not social or educational. The point of uterine existence is to provide the conditions for biological maturation. Decisions in the surrogate uterus called the NICU should have the same purpose. Hence, NICU decision should be left to those who are experts in the biology of the very young. Those experts are physicians who are specialists in newborn medicine.

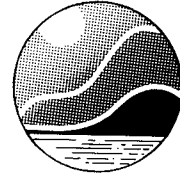
Is there another line of thought which supports parental decision making in the NICU? Try this. It is in the best interests of an infant to be discharged into the home of loving, caring parents. It follows that the NICU has a moral obligation not to discourage parental bonding with the infant since to do so would clearly be contrary to the best interests of their young patient. Presumably the NICU has also an obligation to promote parent-infant bonding. Could we derive from this a role for parental decision making?

It is difficult to see how such an argument would proceed. No doubt, parents can bond with their children in the NICU without making any significant decisions concerning them. After all, many do. Bonding involves loving attachment to the child as being special. Parents who bond with their newborn will want the NICU environment to be best for that newborn. If the argument so far is correct, this entails that wise parents will want physicians to make decisions concerning their infants in the NICU.

### 3. The Realm of Values

The analysis of the above section makes it tempting to conclude that a "doctor knows best" model of decision making is appropriate for the NICU. This model itself is open to two objections. The first is based on the claim that medical knowledge will certainly advance in every area of medicine in the next twenty-five years. From the perspective of that future, doctors don't know best **now**. Indeed, some present procedures may, by that time, have been shown to be injurious.

This objection is sound, but it doesn't entail that doctors don't know **better** than parents. A "doctor knows better" position is sufficient to generate the results of the



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Editor: Alan S. Lubert, Ph.D.

Associate Editor:

Myra Christopher

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410 Archibald, Suite 106

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(816) 756-2713

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argument so far.

The second objection goes like this: physicians are experts in the science of medicine, but the **science** of medicine **never** entails judgments about what **ought** to be done in the hospital, clinic or office. Science is concerned with what is, was, or will be; science itself cannot tell you the **best** course of action in a particular case. Values are a constituent of judgments in the NICU. It is in **this** realm that parents have a role to play in neonatal decision making. Physicians, it might be argued, are experts in medical science; expertise in medical science does not entail expertise in the area of values.

There is a straightforward response to this argument. Physicians are not **merely** scientists, even though their particular expertise is scientific. The Hippocratic duty of physicians, that professional duty special to physicians, is the duty to benefit the sick. Therefore, physicians, **qua** physicians, have the duty to act in the best interest of imperiled newborns, and the best interest of imperiled newborns is to become as biologically independent and whole as possible so that, **after** they leave the NICU, their social and intellectual development can begin. This analysis also leaves little, if any, room for parental decision making.

#### 4. The Interests of the Family

There is a different analysis, however, that one might use to create a role for parental decision making. Even though decisions in the NICU don't impinge on the non-biological aspects of the life of the newborn because such aspects of the newborn's life are minimal, decisions in the NICU do impinge on other aspects of the life of the newborn's family. Some newborns who are discharged from the NICU may be handicapped, some may be severely handicapped. Since families must live for many years with the consequences of aggressive medical treatment in the NICU, surely, it might be argued, parents should have the right to decide whether such aggressive treatment should be undertaken. Parents, it can be assumed, will represent the best interests of their families. It may not be in the best interest of the family to have the burdens of care involved with treating a severely handicapped newborn. These burdens of care can disrupt careers; they can take away time and attention that parents owe to their other children; they can deprive a family of many of the rewards of family life because so much time and attention must be focused upon the needs of the handicapped member. A model of decision making in the NICU based on the Hippocratic ethic does not reflect the fact that infants **belong** to their families. Accordingly, one might argue that, parents, as decision makers for their families, should have a major voice in determining the nature of the care of a newborn.

Notice how this argument is different from the arguments of section 2. The arguments discussed, and rejected, in section 2 opposed a "doctor knows better"

ethic on the basis of **other patient centered** values. **Those** lines of argument were rejected because those other patient centered values did not apply to newborns. However, the line of argument discussed immediately above is not based on **patient centered** values; rather it is based upon **family or parent centered** values. It suggests that the interests of the infant are subordinate to or should be understood in the context of the interests of the **family**; the former arguments did not suggest that at all.

What does this family-centered analysis really amount to? Its most important claim is that when there is a situation in which aggressive treatment of a severely imperiled newborn could—or is likely to—result in a family being burdened with a child who has substantial handicaps and when raising such a child would not be in the interests of the family as a whole, parents may decline to authorize such aggressive treatment.

We have not found a separate role for the values of the family in decision making in the NICU. The analysis suggests that there are very few circumstances in which parental decision making in the NICU can be justified.

One problem with this claim is that it is contrary to law. In Bloomington, Indiana in 1982 the parents of an infant born with Down's Syndrome and with a defect in the digestive tract incompatible with life refused to authorize surgery to repair the defect. The infant died. The executive branch of the federal government reacted by issuing regulations, which have since been struck down by the courts. However, the Congressional response to the Baby Doe episode endures. In 1984 Congress passed amendments to the Child Abuse and Neglect Prevention and Treatment Act which specified conditions under which refraining from medical treatment would count as medical neglect of newborns. Generally, medical neglect is withholding "treatment... which will be most likely to be effective in ameliorating or correcting all such (life-threatening) conditions..." (1) Infants who are irreversibly comatose, (2) infants for whom such treatment would only prolong dying, not correct all of the infant's life threatening conditions or be useless in ensuring the infant's survival or (3) infants for whom such treatment would be "virtually futile" and inhumane are the only exceptions to this doctrine of medical neglect. The effect of this law is to rule out parental decisions to withhold life prolonging treatment of their infants on the basis of the family's best interests. Indeed, broadly put, such legislation mandates treat-

ment for life threatening conditions unless treatment is futile in one way or another or unless the infant is irreversibly comatose. Burdens on the family are simply irrelevant.

Whether or not this Baby Doe legislation is morally defensible **in its entirety** is a difficult question whose answer is far beyond the scope of this short essay. Clearly the **purpose** of the legislation is to defend the view that the life and health of the newborn have moral priority. Neither can be compromised by considerations of the convenience or well-being either of the newborn's family or of the health care personnel in the NICU. And **that** claim seems to be morally defensible by appeal to the following considerations.

We do believe that it is wrong to sacrifice the health or life of an adult member of our family for the convenience or well-being of other members of the family or for the family as a whole. We believe it is wrong to sacrifice the health or life of our older children for the convenience or well-being of other members of our family or for the family as whole. How are imperiled newborns different? On the one hand, they may not have entered into the emotional network of the family. But on the other hand, they appear to differ from other children only by being younger and presumably by being handicapped. However, the principle that it is wrong to discriminate against person because of their age or because of their handicaps seems to be well-established. It follows that imperiled newborns should not be treated differently from other members of our families. Therefore, we have not yet found a separate role for the values of the family in decision making in the NICU. It also follows that we have still not found a role for parental decision making in the NICU.

Is there any other basis for a role for parental decision making in the NICU? One might argue that a best interests standard of decision making is inadequate in the case of **very, very** low birth weight newborns (less than 750 grams) where past raw data in an NICU suggests that aggressive therapy is unlikely to be successful. The basis for this conclusion might be that **because** it is **unlikely** that aggressive treatment is in the best interests of the newborn, the best interests standard cannot be used to justify aggressive treatment or to prohibit withholding treatment. Because the best interests standard does not apply, parental decision can take its place.

A difficulty with this argument emerges when we consider an analogy. Suppose some workers are trapped in a mine. Suppose we estimate that the chances of rescuing them are one in four and then only if the rescuers make extraordinary efforts. Surely it is in the best interests of the trapped miners that we make those efforts. And surely it would be morally wrong not to make those efforts. This analogy suggest that even a less than 50% success rate with very low birth weight newborns does not create "moral

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fidentiality is breached, then it shall be a Class "C" misdemeanor.

**II. ANSWERS TO QUESTIONS ABOUT DUTY TO WARN IN KANSAS**

**A. Are there any state laws in Kansas regarding information to be given to the family of an AIDS patient?**

The only law which might apply in these situations is K.S.A. 65-2892. This law provides that examination and treatment of a minor for venereal disease can be performed with the consent of the minor only. The statute does provide that the physician may but is not obligated to, inform a spouse, parent, custodian, guardian or fiancée of such person as to the treatment given or needed without the consent of such person. Inasmuch as AIDS is considered a venereal disease by some, it is arguable that in the case of minors, K.S.A. 65-2892 might apply. It is unfortunate, however, that K.S.A. 65-2892 refers to fiancée rather than sexual partner. The statute might imply that a physician could inform a sexual partner, but it certainly does not state that.

With respect to adults, there is no law in the state of Kansas about the duty to warn or inform the sexual partners of AIDS patients. There is a growing body of law outside of Kansas accompanied with the recommendations of the American Medical Association that information be given to sexual partners of a person with AIDS or a person who is HIV-positive when such person declines to inform those persons.

There is no body of law anywhere that authorizes the disclosure of patient confidences to persons not at risk to contract the disease. Unless family members are sexually involved with an individual who is HIV positive or who has AIDS then, based upon the current information about the transmission of the HIV virus, there would be no legal support for informing the family of the diagnosis.

**B. If an AIDS test is positive and reported to the state, is there a follow-up by the state with the sexual partner(s)?**

Kansas law does not require that positive HIV tests be reported to the state. The new Kansas law which deals with AIDS does give the Secretary authority to follow persons who are confirmed AIDS victims and to make regulations for the prevention and control of AIDS and for such other matters relating to cases of persons who have AIDS as may be necessary to protect the public health. At this time, there are no rules and regulations for follow-up with sexual partners.

**C. Should the spouse be told that the patient tests positive? Would this be a breach of confidentiality between patient and his/her physician?**

As stated above, there is a body of case law along with the most recent AMA statements, that this information can be given to the sexual partner only in the situation where the physician is sure that the pa-

tient will not inform the sexual partner and it is clear that that person is currently sexually active with the patient and where there is no follow-up by the state.

Yes, such a disclosure would be a breach of confidentiality between the patient and his/her physician. That is why the duty to warn another individual should not be taken lightly and such individual should be warned only when it appears that there is no other way to let him know. Right now there is a case in Johnson County in which the Court has been asked to determine whether or not a physician should disclose to the patient's estranged wife that the patient is HIV-positive. One of the physician's concerns is that the wife expects there to be a reconciliation with her husband and does not know that he is HIV-positive.

*Mary Beth Blake is a practicing attorney in the Kansas City area.*

**Decisions**

room" for parental discretion.

**5. Two Occasions for Parental Involvement**

Is there no role at all for parental decision making in the NICU? There are two occasions in which parents legitimately may be called on to make decisions. First, it sometimes becomes apparent that an infant is not going to survive. A decision needs to be made concerning how the infant will die. It is proper that parents be consulted in such situations because the long term interests of the newborn are no longer of paramount concern and what is important is that the parents be allowed to "let go" and to grieve in a way that is their own and that is humane. Second, parents must be asked for informed consent if physicians wish to perform an experimental procedure on an infant. This is important not only because it is legally required, but also because it is important that consent be obtained from someone who, presumably, will make a decision in the best interests of the infant, and who does not (as the physician may) have a special interest in the completion of the research.

**6. Conclusion**

The analysis of this essay suggests that there are very few circumstances in which parental decision making in the NICU can be justified. The strategy of this essay was to consider arguments that might be offered as a basis for parental decision making in the NICU and to suggest that those arguments are weak. A disadvantage of such a strategy is that it leaves open the possibility that there are arguments for parental decision making that were not considered in the body of the essay. An advantage of this strategy is that it leaves open the possibility of further dialogue.

*Don Marquis, Ph.D., is Associate Professor of Philosophy, University of Kansas*

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