Futile Care in Neonatology: An Interim Report from Colorado

by Peter Hulac and Elizabeth Barbour

A group of Colorado citizens, parents and health care professional has begun work on the problem of aggressive medical treatment in cases when such care appears futile or inappropriate. The group is part of a larger project called GUIDe (Guidelines for Intensive Care in Denver). The committee has studied lethal medical conditions, the role of a consultation structure, care of very premature infants, and developed some guidelines about newborns with life-threatening conditions.

Medical decisions about critically ill newborns are among the most excruciating that family members and health care professionals face. The ethical principle of patient autonomy (or parental autonomy) is brought into question when parents request medical care which is highly unlikely to benefit a newborn infant. Project GUIDe (Guidelines for the Use of Intensive Care in Denver) was developed to address these and other ethical dilemmas that arise in futile care situations. This paper addresses the GUIDe project: its focus, the work accomplished to date, and the work still left to be done in developing paradigms for futile care in the NICU.

Background

Dr. Don Murphy, a gerontologist, established GUIDe in the spring of 1993. Dr. Murphy believed that if an effort to address medical futility was to succeed, it would have to involve dialogue between the lay community and the medical community. Murphy and colleagues discussed the feasibility of the project with many health care professionals before GUIDe was launched. Within two months after the onset of the project, seventy percent of the hospitals in metropolitan Denver had made financial commitments to support GUIDe's staff, as well as contributing supportive effort.

GUIDe is a consortium of health care institutions whose goal is to develop guidelines regarding futile or inappropriate care. The development of the guidelines has been assigned to three subcommittees: adult intensive care, long-term care, and neonatal care. Each group submits quarterly reports to a plenary session which is attended by members of the consortium and other interested individuals from participating institutions and from the community. Suggestions from this session are incorporated into revised proposals.

The Neonatal Subcommittee

The neonatology subcommittee began its work in the summer of 1993. The group includes nurses, parents of physically challenged children, social workers, chaplains, community members, and a representative from each neonatal intensive care unit in Denver. The committee has developed an understanding about the care of infants with

Peter Hulac, MD, is a neonatologist with Colorado Permanente Medical Group in Denver, Colorado. He has served on the general and infant bioethics committees of St. Joseph Hospital in Denver.

Elizabeth Barbour is project director for GUIDe and was instrumental in bringing together the medical community and the public in the collaborative effort. She plans to establish a national network of communities developing similar projects.

lethal conditions, the care of very small and premature infants, some general guidelines about newborns with life-threatening conditions, and a consultation structure.

As the committee began its work, it determined the direction of its initial efforts. Rather than construct a definition of futility, the subcommittee instead described examples of diagnoses in which all members agreed that aggressive care should be stopped, or at times not even initiated (see Table 1). The list was only a guideline since an index of lethal conditions would certainly omit countless diagnoses. Moreover it would not account for individual differences among patients, differences that are best handled on a case-by-case basis.

Table 1

Examples of Lethal Conditions for which Aggressive Care is Futile or Inappropriate

1. Renal Agenesis with Hypoplastic Lungs
2. Anencephaly
3. Cases of Trisomy 18 (in which death will occur without ventilator support)
4. Cases of Trisomy 13 (in which death will occur without ventilator support)
5. Thanatophoric Dwarfism
6. Other Conditions of Similar Magnitude

The neonatal group also studied outcomes of very premature and very low birth weight babies. The Colorado data show that practically no infants born at this altitude before twenty-four weeks' gestation or weighing less than 500 grams survive. The subcommittee recommended that infants who are either lighter than 500 grams or less mature than twenty-four weeks not be resuscitated.

The committee agreed, however, that a group of heavier and more mature infants should be viewed as possible candidates for resuscitation. Decision making about these infants involves careful education of the newborn's family members. The committee recommends that aggressive care should be initiated unless the infant's parents give a well-informed refusal. Decisions about these children whose medical conditions fall into a "gray zone" should be made collaboratively by the physicians and the parents. One of the subcommittee's major efforts in the future will be to reach public consensus about the upper limits of this gray zone. The questions at the end of this article apply particularly to members of this group.

Initial decisions to begin aggressive care need to be reconsidered when other significant diagnoses develop. Examples of such conditions are severe abdominal, pulmonary, or intracranial complications.

The subcommittee also drafted a list of guidelines pertaining to situations in which lethal conditions are present in a newborn infant (see Table 2).

It is recommended that a small group of neonatologists function as medical consultants for families and health professionals dealing with serious questions about life-threatening conditions. This group should be available on short notice to provide support in difficult situations. The group doesn't substitute for a hospital bioethics committee, but instead provides objective information, including state-wide perspectives, in difficult situations. The consultation service will, for example, provide parents, professions, and local ethics committees information about the medical outcomes for similar infants in other Colorado hospitals.

Initial Community Reaction to Project

The findings and recommendations of the subcommittee have been, for the most part, welcomed by Colorado neonatologists and the community. Two criticisms, however, have been offered. The first is that providing guidelines might be interpreted as too authoritarian in an era when we try to make decisions more collegially. The other concern is that many neonatal advances in recent decades resulted because of a lack of rules, or be-

Table 2

Guidelines for the Management of Newborns with Lethal Birth Conditions

Lethal birth conditions affect only a small number of newborns. In this context the word lethal implies that death is expected to occur within infancy. Examples of conditions included in this group are: Trisonomy 13 or Trisonomy 18 requiring life support, renal agenesis, anencephaly, and thantophoric dwarfism.

Supported care is provided for all babies. This includes family contact, oral feedings, hospice or home care when possible, as well as warmth and pain control. Medical professionals will provide appropriate pain control with these patients, even though some medications carry risks, including respiratory or cardiac arrest.

Intermediate care decisions are best made by the baby's family in consultation with the professional care givers. Examples of intermediate care are intravenous fluids (IV), oral medications, supplemental oxygen, and nasogastric tube feedings.

Aggressive care for these babies is inappropriate. Examples of aggressive care include ventilator support, medications to maintain vital signs, CPR, total IV nutrition, and gastrostomy tubes.

A physician in the delivery room may be able to make a diagnosis of a lethal condition. In these cases it would be appropriate *not* to institute ventilator support. In cases in which the professional care giver is not sure of the delivery room diagnosis, it is appropriate to begin aggressive intervention, obtain the appropriate studies, and then withdraw the intervention if the diagnosis of a lethal condition is confirmed.

Bereaved families deserve the highest level of human support, one that recognizes cultural, ethnic, and religious differences. Examples of the types of support which should be made available:

- compassion/support groups
- follow-up case
- bereavement counseling
- hospice counseling
- genetic counseling
- organ donation information
- burial and funeral information
- autopsy information/support

cause we deliberately broke unofficial rules set up by previous generations of physicians. These critiques and others will be considered by the committee.

Questions to be Addressed in the Future

The issue of guidelines for futile care in neonatology is complex. Questions that still require attention include the following:

Can parents refuse life-saving care for a moderately ill or moderatelypremature baby?

Can parents refuse care for a slightly ill or slightly premature baby?

What are the duties of health care professionals in such situations?

Does the public have any voice in these difficult situations?

Should we develop birth weight or gestation age limits above which all infants should be treated even if their parents refuse?

How should individual conflicts be managed?

What role can a hospital ethics committee play?

Future Plans

After the three subcommittee's proposals have been approved within GUIDe, they will be presented to the larger medical community and to the public for additional input. The goal is to establish public consensus. A public liaison subcommittee and a variety of survey researchers will assist this process.

Final guidelines will ultimately be shaped by health care professionals and the public. GUIDe will then present these guidelines to individual hospitals. Guidelines are expected to be implemented within three years.