

Professional Associations Fearful Of Rule On 'Handicapped' Infants

By Judy E. Fox

WASHINGTON—A new government regulation requiring a warning notice to be posted in hospital nursery wards is being decried by various medical associations as a danger to the practice of medicine—and to all infants.

The controversial rule mandates that a sign be posted "conspicuously" in all nurseries, intensive care units and pediatric and maternity wards stating that "discriminatory failure to feed and care for handicapped infants in this facility is

prohibited by federal law."

A national hotline for calling in complaints and violations has been established, and violations could result in a denial of federal funds to the hospital in question.

HHS has identified an investigator for each of the department's regions to respond to the hotline calls. In some cases, however, the state social service agency may investigate charges made in a call.

While the HHS investigators are not

medically trained, a neonatologist will be available in each region for consultation.

The regulation, which was proposed by the Department of Health and Human Services and became effective on March 22, was spurred by the highly publicized "Baby Doe" case, in which a Bloomington, Ind., infant with Down's syndrome was allowed to starve to death.

The infant died after his parents and physicians decided not to operate on his blocked esophagus and to withhold all nutrition and treatment. A lower court upheld the parents' right to make that decision.

While Public Health Service surgeon general C. Everett Koop insisted that the rule was designed to prevent what he called widespread "infanticide," medical groups adamantly have disagreed with it.

Associations Criticize HHS Rule On Infants

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The regulation "would inject federal investigators into the pediatric wards of this country in a way that is dangerous to the health and lives of seriously ill infants," nine medical groups led by the American Academy of Pediatrics, the National Association of Children's Hospitals and Children's Hospital Medical Center of Washington, D.C., asserted at a press conference here.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research agreed with the medical groups. The regulation would dangerously result in "regulators replacing physicians at the bedside..." the commission said.

"Current concerns need not result in a spate of new statutes and regulations—indeed, it would seem foolish to do so," chairman Morris Abram said at a press conference announcing the commission's most recent report on patients' right to forego life sustaining treatment.

"Instead of adding further uncertainty to an already complex situation, the federal government would do better to encourage hospitals to improve their procedures for overseeing life-and-death decisions, especially regarding seriously ill newborns," Alexander Morgan Capron, the commission's executive director, elaborated.

The American Academy of Pediatrics and other medical groups have filed suit in a Washington, D.C., federal court to halt the rule because they say adequate time for public comment and debate was not allowed. (The rule took effect only 15 days after it was proposed.)

However, the groups admitted they will file a separate suit to stop the rule if, after additional comment time, the rule still is implemented.

The American Medical Association also announced it has written to HHS secretary Margaret Heckler urging her to allow additional comment time.

Dr. Koop, a former activist in the antiabortion movement, said at a press conference called in response to the suit that the rule is necessary "to save the lives of children in jeopardy... (and) the rule does not require prolonging the act of dying, rather, protecting the act of living through appropriate nourishment and care."

The National Right to Life Committee has applauded the rule, as has the National Association of Retarded Persons.

But the medical groups and the ethics commission said they believe that everyone has the same interest at heart: protecting the lives of all children, including handicapped children. The difference arises in the methods that should be used to protect those lives, they said.

There are problems with a directive that uses such a general term as "handicapped" and in which each case is not examined individually by competent physicians, informed parents, clergy and social workers, they asserted.

"We believe that hospitals should set review committees, similar to existing investigation review boards, to examine specific cases," Dr. James Strain, president of the American Academy of Pediatrics, stated.

"To inject non-medical concepts of appropriate care into complex situations and highly sensitive situations—and without regard to the role of parents and even, perhaps, clergy—may be destructive to children's interests...."

"Could (government investigators) know, for example, of the controversy regarding whether the closure of a spinal defect in an infant also afflicted with

hydrocephalus might have to be delayed until the hydrocephalus has been relieved?" Dr. Strain said.

The President's ethics commission also recommended that hospitals establish ethics committees to handle these issues as they arise, rather than interject the government into the decisionmaking process.

"Hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants. Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone," the commission concluded.

Cases where the physician and parents disagree might also be reviewed, it said. "Such a review could serve several functions, and the review mechanism may vary accordingly. First, it can verify that the best information available is being used.

appropriate. Third, it can resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute.

“Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate,” the commission concluded.

There are some handicaps which justify a decision not to provide life-sustaining treatment, though it does not believe Down’s syndrome—as in the Baby Doe case—is such a case, Capron related.

“Permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant....

“The handicaps of Down’s syndrome are not in themselves of this magnitude and do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract.

“This is a very strict standard in that it excludes consideration of the negative effects of an impaired child’s life on

Dr. C. Everett Koop

Regulation needed to prevent ‘infanticide’

“Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is

other persons including parents, siblings and society," Capron added.

How would the Baby Doe case have been handled differently if the commission's guidelines been followed? The decisionmaking process would have followed three definite steps, Dr. Joanne Lynn, the commission's project director for this report, related.

First, the parents would have been presented with the child's need for surgery and the physicians' recommendation for that surgery. If the parents still felt that they didn't want the surgery, the case would have gone to the hospital's ethics committee, Dr. Lynn explained.

The hospital committee would then have reviewed the case to make sure that the parents had been given information on Down's syndrome children that have grown up to lead almost normal lives, and other relevant information.

Then if the committee and the parents still disagreed, the state social service agency would have been asked to intervene.

Using this three-step process, the committee would have been able to assure that all decisions had been made with all the information possible avail-

able to the decision makers, Dr. Lynn related.

The commission's report on foregoing life sustaining treatment also included discussion of the medical ethics involved in several other areas:

- Not starting treatment versus stopping it. The distinction between failing to initiate and stopping therapy—that is, withholding versus withdrawing treatment—is not itself of moral importance, the commission asserted.

Moreover, erecting a higher requirement for cessation might unjustifiably discourage vigorous initial attempts to treat seriously ill patients that sometimes succeed, it said.

- The appropriate range of treatment options for dying patients. Until it is quite clear that a patient is making an informed, deliberate, and voluntary decision to forego life-sustaining interventions, health care providers should look for and enhance any feelings the patient has about not yet acquiescing in death, the commission said.

As death comes closer, such sentiments generally recede; until then, there need be no haste to encourage a patient's acceptance of death, it added.

- Limiting care because of cost. It is

Dr. Joanne Lynn

Guidelines help ensure informed and competent decisions

appropriate to take both the significance of the care to the individual and its cost into account in deciding what constitutes adequate care and what

burdens are excessive—society is not obligated to provide every intervention that the patient or provider believe might be helpful.

But, the commission added, explicitly restricting treatment decisions on financial grounds poses significant dangers.

•“Do not resuscitate” orders. Patient self-determination is especially important in decisions for or against resuscitation, the commission said. Such decisions require that the value of extending life—usually for a brief period and commonly under conditions of substantial disability and suffering—be weighed against that of an earlier death, it said.

In decisions concerning competent patients, first importance should be accorded to patient self-determination, and the patient’s own decision should be accepted.

In cases where a surrogate and physician disagree, as when only one thinks that resuscitation is warranted, the case should be reviewed through intrainstitutional consultation or ethics committees, and ultimately to the courts if necessary, the commission said.

However, in urgent situations during such proceedings, resuscitations should be attempted if the situation arises, the commission concluded.

•Permanently unconscious patients (like Karen Quinlan). The interests of the permanently unconscious patient in continued treatment are very limited compared to other patients, the commission said.

Some courses of care are unacceptable because they would fail to respect a patient’s living body or would constitute an irresponsible stewardship of a community’s resources, it said.

Where there are treatment options open to the patient, and there is no advance directive from the patient, the option actually followed should be the one selected by the family.

•Deaths from acts versus omissions. The distinction between acting and omitting action provides a useful rule-of-thumb by separating cases that probably deserve more scrutiny from those that are likely not to need it.

Nonetheless, the mere difference between acts and omissions—which is often hard to draw in any case—never by itself determines what is morally acceptable, the commission said.