

## Presidential Address American Pediatric Society

# Medical Ethics and the Law<sup>1</sup>

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The ethics involved in medical decision making comprise a delicate fabric. Difficult, complex, emotionally laden, and intellectually challenging decisions posing medical and moral dilemmas for which options may present some unacceptable aspects confront every physician from time to time. These decisions are particularly worrisome to the pediatrician who deals with patients unable to express their own wishes. Such decisions may become an almost unacceptable burden in the daily life of a neonatologist. Attempts by government to legislate societal behavioral patterns which are not thoroughly acceptable and ingrained as mores in that society have invariably failed. Sometimes sooner, sometimes later, they are repealed. But changing unworkable laws, like changing bad governments, takes time; and the process is preceded by changing public attitudes about not only what is acceptable behavior, but also attitudes toward priorities of costs incurred under the law in a time of cost containment.

Nowhere has governmental intrusion had such potential influence on behavior and priorities as in the regulations involving ethical decision making in the practice of medicine. The bureaucracy of such legislation is cumbersome but, if effective, could be overlooked. The legal abrogation of the medical conscience and of the responsibility of the physician regarding his patient cannot and should not be tolerated. The recent passage of the Child Abuse Amendments to Public Law 98-457, the so-called Baby Doe Law, was a compromise effort on the part of congressional lawmakers, professional organizations involved in the provision of health care to newborn infants, and various advocacy groups. As such, the law completely pleased none of these constituencies but was believed to be more acceptable than potentially more restrictive legislation threatened by its congressional authors. The American Pediatric Society (APS) was not a party to the compromise legislation nor were our sister academic societies, the Society for Pediatric Research or the Association of Medical School Pediatric Department Chairmen. In a public statement the reasons for our concerns were announced based on the conviction that each medical and ethical dilemma because of its very complexity could not be resolved in the patient's best interest within the framework of legally mandated behavior but should be considered on a case by case basis.

Passage of the law was followed by proposed regulations which went far beyond the carefully worded compromise and overstepped congressional intent. The APS joined the Academy of Pediatrics, a participant to the original compromise, in strenuously objecting to these changes, both personally to the Surgeon General and in writing to the Secretary of Health and Human Services. The final regulations reflect the impact of such vigorous

opposition and are less prescriptive than the original edition but contain "guidelines" in an appendix. These guidelines, although without the legal impact of regulations, will surely regulate the medical behavior of many physicians.

Was there a logical need for a law to protect the rights and needs of babies? The withholding of appropriate medical care from a Down's syndrome patient currently is not an issue to pediatricians and certainly not to neonatologists who are well informed as to the life history and developmental potential of such patients. The instances of misinformed management decisions regarding such patients must be extremely rare, as they are invariably so well publicized. However, those few patients with chromosomal or congenital defects, however severe and incompatible with a prolonged and humane existence, will not be the ones most affected by the Baby Doe Law. It is those thousands of very low birth weight infants who will be affected, those who are at the questionable edge of salvageable extrauterine life, the aggressive prolongation of which is likely to be physically painful and extremely restrictive emotionally. At worst it can be an ordeal which must be considered inhumane by any civilized standards. These tiny patients are not the only victims of the law; loving parents who grieve for their babies' suffering and whose babies' lives their decisions will no longer influence also are victims. One such baby was Baby Andrew, an 800-g baby whose life was intolerably prolonged despite multiple organ failures and repeated medical disasters, many of which were iatrogenic. He was kept alive despite pleas by caring parents that their baby be allowed a humane and natural death. How many Baby Andrews must we maintain as the price of legislating survival of one Baby Doe?

Under the influence of Baby Doe legislation, a physician faced with the decision of whether to follow a course of treatment which in his medical judgment is in his patient's best interest and coincides with the wishes of the parents, or whether to obey the law, may abrogate his responsibility to his patient and aggressively treat well beyond "reasonable medical judgment" because of fear of later legal action. This opens the possibility of another more subtle type of child abuse now sanctioned by law. How many physicians faced with the threat of a murder will subject themselves to such a risk? Other physicians, unwilling to involve themselves in difficult decision making which takes courage and conviction, will refer all potential problem cases from the hospital of origin to a (level III) neonatal intensive care unit which, stressed to its limits of adequate care, is forced to accept and care over long periods of time for infants who already are clearly unsalvageable. This restricts the ability of the level III unit to accept and care for other potentially salvageable infants.

Nowhere does the law address the huge monetary costs incurred by hospitals, parents, or society for acute and long-term

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care of severely handicapped children, some of whom will survive to be severely handicapped adults. Some of the same legislators who supported the law will almost certainly vote billions for the MX missile while proposing to restrict funds to the handicapped, restrict programs involving the health of infants and mothers, and restrict research funds which might make many of these conditions obsolete. The Reagan administration has been particularly offensive in its expressions of outrage at conscientious medical decision making by physicians and parents and by insensitivity to and lack of provision for the needs of sick infants and children who cannot find a hospital bed because of poverty or overcrowding.

Why are preterm births so high in this country, the most affluent in the world, if our national priorities are correct and if we recognize that many of the causes of prematurity are linked to discrimination on the basis of poverty? Why does the government mandate the salvage of the unsalvageable and then fail to provide either for prevention of prematurity or for humane care of premature infants? The government now assumes authority without responsibility. Neonatologists in intensive care units are among those physicians who spend the longest hours not only caring for their patients but dealing with the parents' deep emotional concerns. They look upon themselves as their patients' most ardent advocates, the parents' friend and advisor, and truly believe that "caring intensively" is one of their major roles. The law now places these physicians and their patients' parents in an adversarial role with their colleagues and with society in general when they consider themselves to have their patients' best interests at heart and to be best equipped professionally to decide the most appropriate course of medical management.

The judicial system is concerned with blind justice, and the law prescribes processes to implement generalities of behavior without consideration of their consequences to the individual if it is considered to be in the general good. The practice of medical decision making cannot be generalized in this way. Each individual case, with its myriad of differences from every other case, must be thoughtfully, objectively, knowledgeably, responsibly, and often prayerfully considered and options presented to the patient, or in cases involving infants and children, to the parents, with the necessary consultation to help them make an informed and responsible decision. It is ironic that the Baby Doe legislation is a part of legislative agendas which include "right to die" laws and "living wills" which accept life's termination in death as an inevitable process, one which may be approached with calmness, with dignity, and with preservation of those qualities which make us human and not inanimate objects to be manipulated by machines. Why are newborns singled out for prolongation of intolerable life when adults are allowed to make such decisions for themselves? It is because some well meaning, overzealous individuals believe they can decide who would be better advocates for critically ill newborns than their parents and their physicians. These same groups may attempt to extend the government's jurisdiction over the rights of adults to die with dignity

when their vital processes dictate and attempt to prolong artificially unwanted, unnecessary, and ineffective treatment of the dying.

The worst feature of the Baby Doe legislation is that it takes away the most necessary ingredient of the ethical practice of medicine, the conscience and sense of responsibility of the physician to his patient, and gives it to a committee. A whole generation of pediatricians could grow up without the need to have a medical conscience, without the need to examine each decision with care, to resolve each dilemma as it arises, to feel identification with his patients' suffering, to grieve with their parents, to lose sleep self-questioning the rightness of a decision, and without the need for courage to act in his patient's best behalf. Every physician—however wise, however experienced—needs help and consultation in such difficult decisions, and mechanisms for such consultation should exist in every setting. However, no committee should usurp the physician's ultimate responsibility to his patient. This is the very essence of medical practice. Consideration of this responsibility should be part of the selection process for medical students; it should be taught by precept and by example to students and houseofficers; and it should be insisted upon by one's colleagues and by society. Responsibility implies self-discipline, availability, relevant knowledge, appropriate consultation, and transfer to others when indicated. When physicians fail to exert these restraints and controls on the physician-patient relationship, legislative redress will be the inevitable consequence.

The APS has considered itself an elite group of highly skilled professionals who place exemplary patient care, teaching, scholarship, the advancement of new knowledge, and leadership at a premium. We gather together each year for the "Rites of Spring" to share new knowledge and promote the welfare of children. The government is progressively eroding the conscientious and responsible practice of medicine and research by laws which will deeply modify our ethical and professional behavior. Baby Doe is just one of a series of ethical problems which legislation will try to solve. Being an elite academic society with a yearly rite is no longer enough. It is time to fight back. This society must develop effective mechanisms to influence legislation which involves children, our relationship toward their care, and research into problems affecting their health and welfare. We must be able to be informed quickly about pending legislation, to evaluate effectively its impact, and to develop an acceptable policy—taking into consideration divergent opinions of our members. Then we need to mount an effective expression of our support or of opposition to each piece of legislation. Our attempts to do this in the past have been reactive and poorly organized. We have begun an organized approach toward a solution, and we must continue to develop these mechanisms and be willing to pay their realistic costs. Above all, we must not sit passively but must actively take part in evolving those mechanisms which will enable us to fulfill our responsibilities to ourselves as physicians, to our patients, and to a humane and democratic society.