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LEGAL ISSUES IN MEDICINE

ASKING THE COURTS TO SET THE STANDARD OF EMERGENCY CARE — THE CASE OF BABY K

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ALMOST two decades ago, Dr. Franz J. Ingelfinger predicted that if physicians kept turning to the courts "to resolve essentially medical matters," the medical profession's unfortunate "dependence on the lawyer in reaching essentially medical decisions will continue."¹ One can argue about what decisions are "essentially medical," but the trend that worried Dr. Ingelfinger has continued, and now physicians and a hospital have sought legal and judicial guidance about how — and whether — to treat an anencephalic infant known as Baby K.

TREATING BABY K

Baby K was born by cesarean section on October 13, 1992, at Fairfax Hospital in Falls Church, Virginia. Anencephaly was diagnosed prenatally, and her mother decided to continue the pregnancy despite recommendations for termination from both the obstetrician and a neonatologist. The newborn had difficulty breathing at birth, and mechanical ventilation was begun. Within days the physicians began urging the mother (the father was only distantly involved) to agree to discontinue ventilation, since it served no therapeutic or palliative purpose and was therefore medically inappropriate. The mother refused. The physicians turned to the hospital's ethics committee and met with a subcommittee composed of a family practitioner, a psychiatrist, and a minister. On October 22 the subcommittee concluded that if the impasse between the physicians and the mother continued, a legal resolution should be sought.

Baby K was transferred to a nursing home on November 30, a time when she was not dependent on mechanical ventilation. Her mother agreed to the transfer on condition that the hospital would take the baby back if her respiratory difficulties recurred. On January 15, 1993, Baby K returned to the hospital for ventilatory support and stayed there until February 12. She has returned at least twice since. At this time she continues to reside at the nursing home. Assuming her diagnosis is correct, she may be the longest-lived anencephalic infant in medical history.²

Fairfax Hospital went to federal court seeking a ruling that it was not obligated to render "inappropriate" medical treatment to Baby K under existing federal and state law should Baby K again come to the emergency department in respiratory distress. The mother's position was that "all human life has value, including her anencephalic daughter's life."³ She has "a

firm Christian faith . . . [and] believes that God will work a miracle if that is his will. . . . God, and not other humans, should decide the moment of her daughter's death."³ The hospital, the guardian ad litem appointed by the court, and Baby K's father all believed that further ventilatory assistance to Baby K was medically and ethically inappropriate.

THE OPINION OF THE TRIAL COURT

The trial judge, District Court Judge Claude Hilton, focused almost exclusively on antidiscrimination legislation in his opinion. Under the Examination and Treatment for Emergency Medical Condition and Women in Active Labor Act (Emergency Treatment Act), enacted by Congress to prevent the arbitrary refusal of treatment to uninsured people ("patient dumping"), all hospitals with emergency departments that receive Medicare funds must treat any person who arrives with an emergency medical condition and must continue treatment until the person's condition is stabilized and the person can be safely transferred.⁴ Fairfax Hospital conceded that respiratory distress was an emergency condition but argued that the statute should be interpreted to include an exception for treatment deemed "futile" or "inhumane" by the hospital physicians. The judge disagreed for two reasons: first, the statute did not contain this exception, and second, even if it did, the exception would not apply to Baby K because her breathing could be restored; therefore, mechanical ventilation could not be considered either futile or inhumane. The judge added:

To hold otherwise would allow hospitals to deny emergency treatment to numerous classes of patients, such as accident victims who have terminal cancer or AIDS, on the grounds that they eventually will die anyway from those diseases and that emergency care for them would therefore be "futile."⁵

Judge Hilton also ruled that section 504 of the Rehabilitation Act⁵ and the Americans with Disabilities Act⁶ both prohibited discrimination against Baby K based on her anencephaly. Finally, the judge ruled that as a general matter of law, "absent a finding of neglect or abuse," parents have the right to make decisions about medical treatment for their children.³ When parents disagree with each other, the judge concluded that the courts should support the parent who decides "in favor of life."³

THE COURT OF APPEALS

On February 10, 1994, the U.S. Court of Appeals, in a two-to-one opinion, affirmed the July 1993 judgment of the trial court.⁷ The appeals court, however, examined only one question in reaching its decision: Did Congress, in passing the Emergency Treatment Act, provide an exception for anencephalic infants (or anyone else) in respiratory distress? The court found the language of the statute clear and unambiguous: hospitals are required to stabilize the medical condition creating the emergency. In the court's words, "a straightforward application of the statute obligates

the hospital to provide respiratory support to Baby K when she arrives at the emergency department of the hospital in respiratory distress and treatment is requested on her behalf.”⁷

In making its case, the hospital suggested four reasons why the rule should not apply to Baby K, all of which were rejected. Two of the reasons merit discussion. The first was that Baby K’s emergency condition was not respiratory distress, but anencephaly. The court disagreed, noting that it was her respiratory distress, not her anencephaly, that brought her to the emergency department. Second, the hospital argued that Congress did not “intend to require physicians to provide medical treatment outside the prevailing standard of medical care” in passing the Emergency Treatment Act. The appeals court seemed to agree with the hospital that the “prevailing standard of medical care for infants with anencephaly is to provide only warmth, nutrition, and hydration.”⁷ Nonetheless, the court held that the statutory language was “unambiguous” and included no such limitation on the hospital’s responsibility to stabilize emergency conditions:

We recognize the dilemma facing physicians who are requested to provide treatment they consider morally and ethically inappropriate, but we cannot ignore the plain language of the statute because “to do so would transcend our judicial function. . . . The appropriate branch to redress the policy concerns of the Hospital is Congress.”⁷

Later in its decision the appeals court reiterated the point: “It is beyond the limits of the court’s judicial function to address the moral or ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants.”⁷ The court concluded that the Emergency Treatment Act makes no exception either for such infants or for

comatose patients, those with lung cancer, or those with muscular dystrophy — all of whom may repeatedly seek emergency stabilizing treatment for respiratory distress and also possess an underlying medical condition that severely affects their quality of life and ultimately may result in their death.⁷

The dissenting judge argued that the Emergency Treatment Act was enacted to prevent patients from being dumped for economic reasons and that since dumping was not an issue with Baby K, the statute was irrelevant. He also argued that it was wrong to consider Baby K’s treatment as involving a series of discrete emergency conditions; rather, her care should be “regarded as a continuum,” since there is “no medical treatment that can improve her condition [of permanent unconsciousness].”⁷

MIXED MESSAGES AND CONFUSED ROLES

Many misjudgments were made in this case, but all relate to the failure to distinguish among medical standards, ethical precepts, and legal requirements. After birth Baby K was given mechanical ventilation. This was a medical misjudgment (assuming the physicians really believed it was medically inappropriate) that may have given the mother the impression that

the doctors would provide medically inappropriate treatment to her child if she so desired. Since the physicians had known for months that she would be delivering an anencephalic baby, the issue of mechanical ventilation should have been resolved with the mother before the birth. If the physicians believed (on the basis of medical standards) that mechanical ventilation was contraindicated, the mother should have been informed that it would not be used and given an opportunity to find alternative care givers. If ventilation was to be used, the goal of this intervention (e.g., to confirm the diagnosis) should have been clearly specified, and support should have continued only until the goal was reached or was found to be unattainable.⁸

The ethics subcommittee at the hospital also misconstrued its role. It seems to have discussed nothing ethical at all. Composed of two physicians and a minister, it gave advice on medical practice and legal strategy, concluding that if the physicians could not reach agreement with the mother, the hospital should seek judicial relief. The subcommittee should have insisted that discussion with the mother continue until a resolution was reached, and it should have tried to facilitate this communication.

The hospital’s administration and attorney seem also to have overreacted, though much more predictably. Instead of supporting their physicians in their application of existing medical standards or encouraging further discussion with the mother, they decided to go to court, because they saw Baby K’s ventilatory support as a legal issue that might affect the institution, rather than an issue of medical practice or medical ethics.

The chief misjudgment by the trial judge was to try to act like a physician. His opinion can best be understood as that of a medical consultant who believes he has been asked one technical question: Can ventilatory support help an anencephalic infant in respiratory distress breathe more easily? His answer was yes.

The judge viewed this as a case of arbitrary discrimination by physicians against a mentally handicapped patient. He was correct that hospitals with emergency departments must provide medically appropriate treatment to stabilize the condition of all emergency patients. The physicians’ desire not to give Baby K ventilatory support was, however, explained not by prejudice or financial concern, but instead by adherence to reasonable medical standards. Thus, the judge was chillingly wrong to equate Baby K (and anencephalic infants as a class) with patients with cancer or AIDS who are injured in automobile accidents. It is because of her anencephaly itself that Baby K cannot benefit from any medical intervention.² Patients with AIDS or cancer can, of course, benefit from emergency treatment.

To treat Baby K is not, however, inhumane (as the physicians argued), since she can neither feel pain nor suffer. But it is degrading to treat her for ei-

ther our own symbolic purposes or those of her mother, because to do so is to treat her as an object — as a means to someone else's ends.⁹ If the mere maintenance of biologic functioning in the absence of cortical function (vitalism) were a reasonable medical goal, physicians would be prohibited from ever discontinuing cardiopulmonary resuscitation in any patient, since it maintains circulation and ventilation. Nor has the judgment about treating anencephalic infants been made only by physicians. Congress and the executive branch have also been involved — the “Baby Doe regulations,” for example, specifically recognized limits on care and the role of reasonable medical judgment in setting those limits.⁹⁻¹¹ The regulations themselves specified, and Surgeon General C. Everett Koop agreed, that a decision not to treat an anencephalic newborn is not discriminatory if based on a “legitimate medical judgment” that treatment would be “futile,” because such treatment would “do no more than temporarily prolong the act of dying.”^{12,13} A parental request for treatment does not alter the physician's obligation to exercise reasonable medical judgment. The Child Abuse Amendments of 1984 are also consistent with this view.

By the time the case reached the more rarefied atmosphere of the Court of Appeals, the outcome was predictable. In answering its narrow question about the reach of the Emergency Treatment Act, the appeals court was correct: Congress provided no exceptions for anencephalic infants. On the other hand, I think the hospital was also correct in asserting that Congress did not intend to require physicians to provide emergency care “outside the prevailing standard of medical care.” Certainly, neither side could point to any statute by which Congress has ever required physicians to violate existing standards of medical care. Nor is there any evidence that Congress intended to amend or in any way change the Baby Doe rules when it enacted the Emergency Treatment Act. It seems that the appeals court simply believed that the trial court had not acted unreasonably in favoring a mother who wanted her child treated over a hospital that wanted the child to die sooner rather than later.

THE ROLE OF MEDICAL STANDARDS

The logic of the Emergency Treatment Act as interpreted by these courts, although understandable in context, is incorrect because the technological imperative is limitless. To avoid cases like this one, Congress should have included the phrase “consistent with reasonable medical standards” in its requirement for stabilization. If the legal rule really were that hospitals and physicians had to provide any and all life-saving treatments to anencephalic infants that were wanted by the parents, they could be required to provide not only ventilatory support, but also other types of support, such as kidney dialysis for renal failure, and ultimately a heart-assist device when the child's heart begins deteriorating. As the dissenting judge properly argued, the focus must be on the pa-

tient as a person, not on the patient as reduced to a group of separate organ systems.

It is true that parents have (and should have) wide discretion in choosing among treatment options for their children. In the absence of evidence that a particular decision constitutes child abuse or neglect, we should presume that families can make the best decisions for their children. But it does not follow that physicians must do whatever parents (or adult patients themselves) order them to do regardless of standards of medical practice. Parents can choose among medically reasonable treatment alternatives, but they cannot prescribe treatment or demand that they or their children be mistreated.¹⁴

In the leading Supreme Court case cited by the trial judge, the Court upheld a state statute that permitted parents to commit a minor child to a mental institution without first providing the child with a court hearing.¹⁵ But it did so only because the Court believed that the psychiatrist at the institution would act in the best interests of the child and not admit him or her unless the psychiatrist made an independent medical assessment that institutional care was in the child's best interests.^{9,15} In another case, the Court ruled that retarded persons in state custody have a constitutional right to habilitation but that the content of that right should be left to the judgment of medical professionals.¹⁶

Thus, it is not the law that physicians must do whatever parents want. Rather, the law that parents should usually consent to treatment decisions made for their children is based on the premise that physicians will exercise independent medical judgment and not follow parental orders if the physician believes they are not in the best interest of the child or patient. In passing the Emergency Treatment Act, Congress was responding to situations in which physicians were refusing to treat patients in emergencies for economic reasons — not because of an exercise of medical judgment or standards of medical practice.

Because medicine has become a consumer good in many respects, and because many physicians and hospitals treat medicine as a business in which medical services are provided on the basis of the patient's desires rather than medical indications, it is becoming more and more difficult for physicians to refuse whatever patients and their families demand. Thus, for example, it is impossible for physicians to argue credibly that treating patients in persistent vegetative states is contrary to standards of medical practice, because most physicians actually provide continuing treatment if the family insists.^{17,18} Treating medical care as a consumer good is a central reason why medical costs are out of control and why a national health plan that gives physicians financial incentives not to treat seems attractive to many policy makers.

WHAT SHOULD BE DONE?

Before the case of Baby K, the medical standard of practice was to provide no artificial ventilation to

anencephalic infants. Now, physicians in emergency departments are legally obligated to provide assistance, ventilatory and otherwise, to anencephalic infants who need it to survive. Emergency physicians can live with this rule, because the case is not likely to arise again.

There are three possible scenarios for the future. In the first, physicians will do whatever patients want (as long as they can pay for it), because medicine will be seen as a consumer commodity like breakfast cereal and toothpaste. This will make medicine even more unbearably expensive than it is. Therefore, the second scenario, a variation on Dr. Ingelfinger's vision, is more likely. The task of defining "appropriate medical care" will be removed from physicians altogether and put in the hands of payers and government regulators, who will decide the content of medicine.

To avoid either of these scenarios, physicians must work toward a third, in which they not only set standards for medical practice, but also follow them. Physicians cannot expect parents, trial-court judges, insurance companies, or government regulators to take practice standards more seriously than they do themselves. If physicians cannot set standards for the treatment of anencephalic infants and adhere to them, standard-setting by physicians is a dead issue.

REFERENCES

1. Ingelfinger FJ. Legal hegemony in medicine. *N Engl J Med* 1975;293:825-6.
2. The Medical Task Force on Anencephaly. The infant with anencephaly. *N Engl J Med* 1990;322:669-74.
3. In the Matter of Baby K, 832 F.Supp. 1022 (E.D. Va. 1993).
4. Emergency Medical Treatment and Active Labor Act, P.L. 99-272, 42 U.S.C. sec. 1395dd (1985) (renamed in 1989).
5. Rehabilitation Act of 1973, P.L. 93-112, 29 U.S.C. sec. 701-796i (1973).
6. Americans with Disabilities Act, P.L. 101-336, 42 U.S.C. sec. 12101-12213 (1990).
7. In the Matter of Baby K, 16 F.3d 590 (4th Cir. 1994).
8. Paris JJ, Schreiber MD, Statter M, Arensman R, Siegler M. Beyond autonomy — physicians' refusal to use life-prolonging extracorporeal membrane oxygenation. *N Engl J Med* 1993;329:354-7.
9. Elias S, Annas GJ. Reproductive genetics and the law. Chicago: Year Book, 1987.
10. United States v. University Hospital, State University of New York at Stony Brook, 729 F.2d 144 (2d Cir. 1984).
11. Office of Human Development Services, Dept. Health & Human Services. Child abuse and neglect prevention and treatment program; final rule. *Fed Regist* 1985;50(72):14878-901.
12. Krushe H, Singer P. Should the baby live? New York: Oxford University Press, 1985.
13. Office of the Secretary, Department of Health and Human Services. Nondiscrimination on the basis of handicap relating to health care for handicapped infants; proposed rules. *Fed Regist* 1984;49(8):1621-54.
14. Annas GJ. Judging medicine. Clifton, N.J.: Humana Press, 1988.
15. Parham v. J.L. and J.R., 442 U.S. 584 (1979).
16. Youngberg v. Romeo, 457 U.S. 307 (1982).
17. Miles SH. Informed demand for "non-beneficial" medical treatment. *N Engl J Med* 1991;325:512-5.
18. In re Wanglie, No. PX91-288 (Prob. Ct., Hennepin Co., Minn., June 28, 1991).

BOOK REVIEWS

"DIVULGING OF USEFUL TRUTHS IN PHYSICK:"

THE MEDICAL AGENDA OF ROBERT BOYLE

By Barbara Beigun Kaplan. 216 pp. Baltimore, Johns Hopkins University Press, 1993. \$40. ISBN 0-8018-4601-3.

The applicability to modern medicine of Newton's comment about "standing upon the shoulders of Giants" is vividly brought home to the reader of Barbara Kaplan's book on Robert Boyle. By repeatedly presenting information about the great natural scientist in its historical milieu, Kaplan dramatically portrays the groundbreaking importance of Boyle's contribution to modern science, and modern medicine in particular.

In the 17th century, the sharp lines between what is now considered medicine and the other scientific disciplines either were not drawn at all or, at best, were very fluid. Hence, though Boyle's only medical degree was an honorary one conferred on him late in life, it was not considered inappropriate in those times for a great natural scientist to have ideas and suggestions crossing over into the field of medicine.

Kaplan begins by giving us a sense of the climate of the times. Medicine was a learned profession, but its learning was mostly gleaned by looking backward. Galenic medicine and its philosophy all but reigned supreme. Medical factionalism and religious sectarianism were widespread. The author shows how Boyle's lifelong commitment to irenic Protestantism carried over into his scientific philosophy. Consequently, we see his repeated calls for cooperation among the researchers in a field as well as on an interdisciplinary level. Boyle's emphasis on the empirical method of scientific investigation was revolutionary; his insistence on

the tentativeness of his conclusions was refreshing (as it would be today).

The presentation of Boyle's major contributions is skillfully interwoven throughout the book. For example, one of Boyle's key scientific insights was his corpuscular hypothesis (a remarkable foreshadowing of the atomic hypothesis). This is not merely catalogued and then dropped; rather, its importance to science and medicine is developed throughout the book. Similarly, the integration of his major ideas can be seen in Kaplan's presentation of Boyle's insight regarding causes of disease, "effluvia," and the uses in medical treatment of specific chemicals either alone or in combination, in contrast to the prevailing generalized approaches of Galenic medicine, such as the widespread use of purgatives and bloodletting.

Carefully researched and thoroughly referenced, the book admirably succeeds in sticking to its thesis of illustrating the medical agenda of Robert Boyle. Readers will have to look elsewhere if they expect to find out how Boyle's law came about.

This is not a biography of Boyle, yet it contains tantalizing biographical fragments; bits about Boyle's hypochondriasis, the disorganized state of his work and his papers, his poor vision and his particular interest in eye disorders, his distrust of doctors, and his interest in developing his own drugs (one of his favorite recipes was the *ens veneris*) make one eager to learn more about him as a man. The reader hoping for more must turn to a more traditional biography of Boyle, perhaps R.E.W. Maddison's *Life of the Honorable Robert Boyle* (New York: Barnes and Noble, 1969).

Although this book will appeal most to those interested in medical history, it would be unfortunate if students considering entering the field of medicine and physicians already engaged in its practice were to deny themselves the opportu-