

Decisions Regarding Treatment of Seriously Ill Newborns

Norman Fost, MD, MPH

THERE HAS BEEN A REMARKABLE TRANSFORMATION DURING the past 15 years in the process and substance of decisions regarding medical treatment of seriously ill and handicapped newborns. For thousands of years, parents exercised virtual ownership over their infants.¹ Infanticide was common in Western Europe until late in the 19th Century.^{2,3} In the United States during the 1970s, standard medical treatment for curable disorders was commonly withheld from infants with Down syndrome, a practice that was supported by two thirds of pediatricians.^{4,5} In 1983, a major medical center reported that standard treatment was withheld from more than half of a cohort of infants referred with spina bifida.⁶ These decisions were often driven by directive counseling by the infants' physician, with or without the consent of the parents. Courts were generally supportive of the rights of biologic parents to make such decisions, even when it was implausible that withholding treatment was in the child's interests.⁷

In the 1980s, all this changed. The case of "Baby Doe," an infant with Down syndrome and esophageal atresia who died without surgical intervention, was used by the Reagan administration as a focal point for federal regulations, eventually supported by a statute providing funds to the states for programs to combat child abuse.⁸ The definition of child abuse was changed to include "failure to provide medically necessary treatment." The Baby Doe regulations created a new substantive standard: namely, the prospect of handicap should play no role in treatment decisions.⁹ Exceptions were allowed for infants in irreversible coma, for treatments that were futile, and for treatments that were "inhumane," although the definition of that term has been the subject of continuing controversy.¹⁰⁻¹²

The Baby Doe rules also were accompanied by an acceleration in the development of hospital ethics committees.¹³ While not strictly required by the regulations, they were strongly recommended,¹⁴ and hospitals and medical associations increasingly perceived these committees as having several virtues, including the prospect of averting more onerous federal intervention. As a result, decision making about treatment of critically ill and handicapped infants be-

came more collaborative, including professionals and occasionally lay persons who work outside of the newborn intensive care unit.

While it is difficult to trace cause and effect precisely amid major social change, it is clear that neonatal care has changed dramatically. It is difficult to find a single case of withholding life-sustaining treatment from an infant based on a diagnosis of Down syndrome or spina bifida since 1985. While neonatologists continued to recommend withholding or withdrawing life-sustaining treatment based on expectations of quality of life, such decisions shifted to extremely low-birth-weight infants, usually with major intracranial hemorrhage or multiorgan system failure, ie, infants whose prospects for meaningful life were considerably more bleak than those with Down syndrome or spina bifida.

Concurrent with the dramatic decline in controversial cases of withholding life-sustaining treatment, there was an increase in prolonged and intensive treatment of infants with poor prospects for meaningful life.^{15,16} A prolonged history of what is now perceived as serious undertreatment of infants with reasonable prospects for living a meaningful life was replaced by an era of serious overtreatment. One form of child abuse, neglect, was replaced by a form of medical battering. In both cases, the interests of the patient seemed to be a casualty.

In the ideal setting, the interests of the infant patient would be paramount, which is not to say absolute. No patient is entitled to infinite resources from his or her family or from society. In the best neonatal intensive care units today, clinicians and parents, sometimes with the help of ethics consultants or committees, work collaboratively in an effort to promote and protect the infant's interests while taking reasonable account of the parents' wishes and interests. The problem is how to define the best interests of an infant with an ambiguous future, and how much to weigh the opinions of the key players—the parents and the health care professionals. It has generally been considered improper or meaningless to speculate about presumed wishes of the infant, since these are unknowable.

While the infant's wishes are unknowable, decision makers sometimes consider the views of older children or adults

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Author Affiliation: Department of Pediatrics and Program in Medical Ethics, University of Wisconsin Medical School, Madison.

Corresponding Author and Reprints: Norman Fost, MD, MPH, Department of Pediatrics, University of Wisconsin Hospital, 600 Highland Ave, Madison, WI 53792 (e-mail: normfost@macc.wisc.edu).

with similar conditions as a way of including the patient's perspective. In this issue of *THE JOURNAL*, Saigal and colleagues¹⁷ present new information that may help elucidate this decision-making process. The authors compared the preferences for selected hypothetical health states from the perspectives of health care professionals (ie, neonatologists and neonatal nurses), adolescents who had been extremely low-birth-weight infants, and their parents. Their main findings demonstrate that the adolescents and their parents tend to rate their health states higher than what the health care providers tend to rate them. They also suggest these findings may be helpful in including the "patient's perspective" when life and death decisions have to be made in the neonatal period. This suggestion has several limitations.

Good ethics starts with good facts, so new data that might inform the ethical judgments that parents and professionals must make generally should be welcome. However, there are several methodological and conceptual problems with applying the findings to decisions involving identifiable patients.

More detail about the quality of life of the adolescents in this study was provided in an earlier study.¹⁸ Most (89%) of the adolescents who were extremely low-birth-weight infants were cognitively normal or only mildly impaired, and 90% had no mobility problems, although 73% had some neurosensory impairments. It should not be surprising that relatively high-functioning persons valued their lives, or the lives of hypothetical characters who resemble themselves. Most people prefer life to death, even handicapped life. There is rarely disagreement about whether it is worthwhile to save the life of a child who will have mild to moderate handicaps. The more difficult question for those who must make decisions in the neonatal period is whether profoundly handicapped adults (eg, "Pat" in the Saigal study) consider their lives worth living. This, of course, becomes progressively unknowable at the critical point, when it is most desirable to know whether the patient will ultimately value his or her life. The difficulty in learning the views of a profoundly retarded adult is a structural obstacle to obtaining the information that would be of greatest interest.

Even if this question were answerable and even if the answer came back unequivocally, a question would remain about its relevance to the infant's interests. For example, consider an interview with a 50-year-old man dying of Huntington disease. Suppose this man expressed a clear and consistent wish to die, the sooner the better. It would not follow that the same person as a boy aged 1 or 11 or 21 years would also prefer death. This analogy is imperfect since the extremely premature damaged infant is not functionally normal, as would be the 11-year-old boy with the time bomb of the Huntington gene ticking inside of him. But neither is the damaged infant likely to be depressed or worried about his or her future, as the adolescent might be, nor does the adolescent's views shed any light on the relative benefits and burdens of existence for the infant.

From the parent's perspective and perhaps the adolescent's, one of the central reasons for believing a profoundly handicapped child might be better off dead is the disappointment the parent feels from realizing that the child will never fulfill the parent's hopes and expectations. Part of this feeling is an aesthetic one, relating to the dissonance between the growing body and the static mind. No one considers a developmental level of 2 months a disappointment if it is found in a 2-month-old body. But the 2-month-old brain in the 20-year-old body may be viewed as being repulsive. It is unknown how this life is experienced by the infant inside of the body, but the severely damaged infant is unlikely to be concerned about it.

As Saigal et al point out, there are more promising applications of their findings. Their demonstration of the gap between the views of the physicians and nurses on the one hand and the parents and adolescents on the other should be a useful starting point for health professionals who want to work collaboratively with parents. The authors also correctly point out that programmatic decisions, such as how much of a nation's resources should be committed to treatment of its most handicapped citizens, may be influenced by such data, even if individual decisions are not.

It should be considered progress if the debate about treatment of identifiable imperiled newborns is clouded in ambiguity, in contrast to the certainty of the past 2 millennia. There is a broad consensus in the United States that many of the decisions of undertreatment in the past were morally wrong. There is an emerging consensus that prolonged intensive care for certain extremely low-birth-weight infants—less than 22 weeks' gestational age at the least—is extremely unlikely to result in a life that could be construed as being in the child's interests. The debate is increasingly about infants whose prospects are unavoidably ambiguous. The best approach in such cases is to be sure the process is as good as it can be. In the current setting, that means candid conversation among parents, physicians, and other health care professionals; consideration of all the relevant facts and interests; and in extremely difficult or refractory cases, consultation with an ethicist or institutional ethics committee.

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Medical, Legal, and Societal Implications of Androstenedione Use

Charles E. Yesalis III, MPH, ScD

USE OF THE DIETARY SUPPLEMENT AND ANDROGENIC steroid hormone androstenedione¹ presents a number of questions and challenges. Is it a supplement or a drug? Should youngsters be allowed to use it? Should it be sold over-the-counter? Does it work as advertised? Is it safe?

During the past year, the public was exposed to a barrage of drug scandals in sports. These involved Olympic champions in track and field, swimming, and snowboarding, as well as elite cyclists, a 3-time winner of the Boston Marathon, and a professional tennis player.² However, of all the drug-related stories in 1998, none received more media attention than home run record holder Mark McGwire's admission that he used androstenedione as a performance-enhancing substance.³

When questioned, supporters of McGwire borrowed several pages from today's political playbook and argued that what McGwire did was not illegal, was a personal matter, and, besides, the quest for the home run record was good for baseball.³ Nevertheless, while androstenedione is not outlawed in major league baseball, it is on the banned drugs lists of the International Olympic Committee, the National Football League, and the National Collegiate Athletic Association.^{3,4}

Many expressed concern that the use of this agent by sports heroes, who may be considered role models, might encourage youngsters to use this steroid hormone. This apprehension is supported, in part, by the claim by Barry McCaffrey, director of the Office of National Drug Control Policy, that androstenedione use by youngsters has increased 5-fold since McGwire's admission,² as well as by manufacturer estimates that sales of androstenedione have skyrocketed as a result of the publicity.^{5,6} There is a dearth of epidemiologic data on the frequency of androstenedione and other supplement use

by either children or adults. However, the illicit use of anabolic steroids among adolescents is well documented (lifetime use of 4.9% for males and 2.4% for females⁷), and it is logical to conclude that even a larger percentage of adolescents would use a purported anabolic steroid, such as androstenedione, that can be purchased legally.

In this issue of *THE JOURNAL*, King et al⁸ evaluated the short- and long-term effects of oral androstenedione supplementation in 20 healthy young men. The authors found that androstenedione supplementation did not enhance skeletal muscle adaptation to resistance training and did not increase serum testosterone levels.

While King and colleagues have conducted a well-designed study that has provided valuable information, several questions remain and indicate the need for further investigation. For example, of the young men enrolled, only 2 had ever engaged in resistance training, and that training had been more than 1 year earlier. Such inexperienced weight trainers generally make significant gains in the early phase of resistance training programs. These large strength gains could overshadow, statistically, any potential gains from androstenedione.⁹ Conversely, individuals experienced in resistance training have "plateaued" and their incremental gains in strength are smaller as they continue training. In these experienced weight trainers, possible androstenedione-assisted increases, which might be small compared with initial gains by inexperienced lifters, would more likely be statistically significant compared with strength gains by experienced trainers who are not using androstenedione.

King and colleagues' observations that androstenedione decreased high-density lipoprotein concentrations and increased estrone and estradiol concentrations suggest a potential link of this androgenic steroid hormone to heart disease and stroke, and even aggressive behavior.¹⁰ Conse-

Author Affiliation: Departments of Health Policy and Administration and Kinesiology, Pennsylvania State University, University Park.

Corresponding Author and Reprints: Charles E. Yesalis III, MPH, ScD, Department of Health Policy and Administration, Pennsylvania State University, 115 Hendersson Bldg, University Park, PA 16802-6500.

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