

Letter from . . . Chicago

Squeal rules in the nursery

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In April 1982 a couple from the town of Bloomington, Indiana, learnt that their newborn baby boy had Down's syndrome and tracheo-esophageal fistula, as well as possibly other congenital abnormalities. After discussion with the local doctors they decided that no corrective surgery was to be carried out. Members of a right to life organisation sought a court order to require surgery, but the appeal was turned down and the baby died after six days. Though many details of the case remain unknown, being sealed in the records of the courts, the so called Baby Doe incident has continued to generate controversy, highlighting the painful dilemma of what to do with severely handicapped infants.

This year the subject received full consideration by the Presidential Commission on Ethics in Medicine,¹ whose other findings and recommendations I have reported.² Addressing this particular issue in a 33 page chapter, the commission traces the origins of present difficulties to the extraordinary advances that in past decades have revolutionised the discipline of neonatology. In the United States the death rate for babies in the first years of life has been cut by one half within a decade. Since 1961 it has declined from half to 20% for newborns weighing 1000-1500 g, and from 90% to half for infants weighing less than 1000 g. But, despite aggressive management many babies cannot survive, the mortality for babies of less than 700 g is nearly 100%, and the decision when to stop life sustaining treatment has become yet another agonising dilemma brought on by medical progress. At special risk are two categories of infants, those with low birth weights and those, some 4% of all births, who have congenital abnormalities.

These infants, as well as many others, are cared for in the nation's 7500 neonatology intensive care beds in some 600 hospitals by over 1000 neonatologists at an estimated cost of some \$2-3 billion a year. To this must be added considerable expenses after the hospital stay, which makes the issue of caring for seriously ill newborn infants an economic as well as a moral and legal issue. At present decisions to stop treatment are part of the everyday life of a neonatology unit, being usually made by doctors and parents without review by courts or other committees. One disadvantage of this approach, according to the presidential commission, would seem to be that the ethical basis for making decisions is not always clearly understood. Another consequence is the growing number of legal disputes or prosecutions on charges of infant neglect or abuse.

In considering the ethical basis of good decision making, the commission holds that clearly futile treatments need not be given—unless the parents insist that they should. Treatment should be provided when it seems to be clearly in the baby's best interests—with adequate institutional review during the process if the parents should disagree. When the benefits of

treatment seem to be ambiguous or uncertain, the commission believes that the preference of the parents should prevail. In response to and in general agreement with these recommendations an editorial writer in the *Chicago Tribune* noted that, though no universally acceptable solution can ever be devised, a realistic consensus may be reached along the following guidelines.³ Most infants with Down's syndrome should have corrective surgery, if necessary, and should receive all the medical and nursing care provided to normal newborns, because their prognosis has improved and the degree of handicap cannot be assessed in early infancy. Babies with spina bifida should get surgical treatment as quickly as possible. Dying or terminally ill babies need not be resuscitated or given extraordinary treatment, but should be nourished and made as comfortable as possible. Active euthanasia is not acceptable. Final decisions should be made by the parents, as the traditional and legal surrogates for their children. Hospitals and physicians should provide caring support and make available guidelines and current objective information on prognosis. Government agencies, ethics committees, and judges should not usurp this parental responsibility, unless they are prepared to take on lifelong responsibility for severely damaged and marginally existing survivors. Federal funding should not be denied to hospitals in which patients decide that a baby should not be kept alive at all costs, because this would be unfair to the other patients, who have nothing to do with the issue.³

Outdated information given

The report concedes that in the past many difficulties have arisen because patients received outdated information, and that occasionally wrong decisions have been made by both doctors and parents. As a procedural matter, just as in other life and death events, the commission holds that the baby's interest be represented by parents or surrogates. Hospitals should have explicit policies on decision making procedures; ethics committees should provide internal review whenever parents and doctors decide to forego treatment; and only the rare case should be referred to the courts, because legal proceedings are slow, costly, disruptive of care, and likely to generate an adversarial atmosphere. Government regulations likewise should be kept to a minimum, being prone to add further uncertainty to a complex matter,¹ which is precisely what happened in the aftermath of the Baby Doe episode.

Turning to this particular case, we find the events well summarised elsewhere.⁴ In the aftermath of Baby Doe's death the federal government notified all hospitals that it was unlawful to deny medical care to a handicapped baby. This action, apparently precipitated by a memorandum from the president himself, seems to have been taken with the aim of doing something visible for the right to life lobby. In March 1983, for possibly similar reasons, the government sent another order, now requiring hospitals to post a sign in a conspicuous place in delivery rooms and nurseries stating that discrimination against

handicapped infants was prohibited, and warning that federal funds would be withheld from offending hospitals. It also announced the setting up of an investigative agency in Washington, complete with a 24 hour toll free telephone number and with investigator squads ready to fly at a moment's notice to the site of suspected criminal discriminatory action against babies. Over 500 such telephone calls were received in the ensuing two months, mostly hoaxes, but on four occasions Baby Doe investigator squads actually flew to the site of possible misdeeds. They found no violations, but caused considerable anguish to parents as well as upsetting everybody else.^{1 5}

Meanwhile the government regulation unleashed a storm of criticism. Some hospitals refused to post the notice. At the University of California in San Francisco the chancellor was reported to be "enraged and infuriated;" and a sign in the hospital was displayed near the official one, calling the government's edict an affront to the professional staff's commitment and performance. The newspapers, though sympathetic with the goal of preventing inhumane treatment to severely handicapped babies, were also critical. The *Chicago Sun-Times* called the rule wrong in design and implementation, an intrusion on tragedy, and a wrong way to heighten awareness of a sad dilemma, especially when the most humane way might be to offer no treatment at all—and it concluded that the government should get off the people's back and repeal the "squeal rule." The *Wall Street Journal* thought that the government had embarrassed itself and that the administration had acted to satisfy its constituency, and regretted that conservatives had now also concluded that the way to win the game was with laws, rules, and regulations. It also pointed out that the paediatricians and neonatologists who were now being policed in such a peremptory manner were the same ones who had developed these life saving mechanisms and who should possess the high intelligence to make correct decisions. The American Academy of Pediatrics and the American Medical Association thought that the rules were objectionable, indicated that the government had acted precipitously by "interjecting itself and anonymous order into the practice of medicine," and noted that parents and doctors might soon find their decisions reviewed by strangers, perhaps another parent, an aide, or a janitor, who could make a capricious telephone call complaining that a child had not received adequate care.

The judges, it seems, also disagreed with the government's way of doing business. In April, a 72 year old federal judge, son of a noted paediatrician, struck down the Baby Doe rule as being arbitrary, capricious, intrusive, the result of haste and inexperience. He found that the government had failed to follow the usual procedure of first publishing preliminary regulations and seeking public comment; neither had it considered the disruptive effect of any anonymous tipster being able to trigger an investigation leading to immediate review of hospital records and interviewing of patients and medical persons. Commenting on the decision, the *Wall Street Journal* noted that this was about as close a judge would come to saying that something the government had done was basically idiotic.

Plea for saner counsels

The American Academy of Pediatrics, which together with other medical organisations had filed the appeal, was gratified by the decision and hoped that it could work with the government to find a better approach to solving this sensitive problem. But the administration announced that it would appeal against the decision, indicating that when it came to placating its own constituency the conservatives could be as obtuse and meddlesome as the liberals. So, while the federal government is re-writing the regulations, several states are also considering juvenile protection acts that would require medical staffs to report immediately any case where food, nutrients, and other "substances" were denied, failure to do so being punishable

by the suspension of a physician's, nurse's, or midwife's licence. Worse still, we read how in Oregon right to life groups have dragged into court the parents of an infant born with part of its brain outside of the skull, who could not eat, and then died despite attempts to feed it. Congress is also considering several Bills setting up systems to report cases of suspected neglect and threatening to cut off funds from non-compliant states or hospitals. Yet most of these Bills have been opposed by the American Academy of Pediatrics on the grounds that, while one should try to relieve infant pain and suffering, this cannot be achieved by government regulations, hot lines, and investigative squads. It is all a far cry from the Presidential Commission on Medical Ethics, which had sensibly recommended that rather than add further uncertainty to an already complex problem, the government would do better to encourage hospitals to improve their procedures for overseeing decisions on life and death matters. Yet this is not the way of legislatures, often suspicious of elitist doctors and always confident that simply passing new laws will solve a problem. So that, while the last word on this issue has not yet been written, we hope that saner counsels will prevail, lest a dark age of uncertainty and fear should descend on the nation's nurseries.

References

- 1 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavior Research. *Deciding to forego life-sustaining treatment*. A report on ethical, medical, and legal issues in treatment decisions. Superintendent of documents, Government printing office, Washington DC 20402. March 1983.
- 2 Dunea G. When to stop treatment. *Br Med J* 1983;**287**:1056-7.
- 3 Anonymous. Is any baby better off dead? *Chicago Tribune* 1983;May 23: 16.
- 4 Culliton BJ. "Baby Doe" regs thrown out by court. *Science* 1983;**220**: 478-80.

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The basically healthy 1 year old child of a father with lifelong mild eczema has developed an eczema and an allergy to egg white that causes general upset and urticaria on the chin from dribbling. It has been suggested that goats' milk might help the eczema. Is such a trial worth while?

Children with atopic dermatitis are prone to produce IgE mediated (immediate weal type) allergic reactions, as has happened with this child to egg. Allergy of this type is not the whole cause of atopic dermatitis but may nevertheless contribute, sometimes to a considerable extent. Just how often this occurs is now of great interest, both in the scientific and in the lay press.¹ Allergy to cows' milk is the commonest such allergy in young infants and may play some part in 20% or more of cases. Often such allergies become quite insignificant once the eczema has been controlled by any means. Goats' milk is just as likely to sensitise and a change to it will be of value only if the child is already sensitised to cows' milk. There is even some cross reaction between the two milks, certainly in experimental animals.² Some patients who had taken goats' milk for some time improved when reintroduced to cows' milk. Skin tests and laboratory tests are unreliable in predicting which patients should avoid which milk. Most cases of infantile eczema are best treated conventionally. In most of the remainder simple avoidance of suspected foods for two to four weeks, followed by normal exposure, is appropriate. This may need repeating more than once to be convincing. Goats' milk or other milk substitutes may be included or omitted according to the dietary needs. In severe cases of atopic dermatitis, where there may be multiple allergies, a more rigorous diet with controlled reintroduction of foods under the supervision of a dietician may give useful and, just occasionally, dramatic results.—R H CHAMPION, consultant dermatologist, Cambridge.

¹ Brostoff J, Challacombe SJ. *Food allergy*. London: Saunders, 1982.

² McLaughlan P, Anderson KJ, Widdowson EM, Coombs RRA. Effect of heat on the anaphylactic-sensitising capacity of cows' milk, goats' milk and various infant formulae fed to guinea-pigs. *Arch Dis Child* 1981;**56**:165-71.