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Early Management and Decision-Making for the Treatment of Myelomeningocele at the University of Oklahoma Health Sciences Center: Observations Clinical and Ethical

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With news of legal action against the Oklahoma University's Health Science Center, and the inevitable consequences of this suit on behalf of the 24 infants with spina bifida who were not recommended for active treatment, but allowed to die without benefit of surgery, antibiotics or sedation, the time seems opportune, before the nation's media heighten community emotions, to examine the crucial clinical and ethical basis of the OUHSC team's program as published (*Pediatrics* 1983: 72: pp. 450-458), and evaluate calmly, according to criteria which pass the tests of the whole community, their worth and soundness. This legal battle will excite passions and divide this nation. It has the ingredients of a Monday night movie. Its impact on law and medicine in America will be felt for years. For all of these reasons, prior to popular, partisan commentary, I hope this contribution will further the reflection among the health care communities closest, most involved — and with the most to lose and gain.

The Selection Issue

Spina bifida has existed throughout human history. Hippocrates was aware of the condition, and the teacher in Rembrandt's "The Anatomy Lesson" illustrated spina bifida in 1652 and gave it the name we use. In the treatment history of the condition as outlined by John Lorber,¹ from the beginnings of the human race until the late 19th century, spina bifida was

not treated, as no procedure was seen as beneficial. The great majority of sufferers died in their infancy, as they did from the other scourges of newborns.

Apart from some isolated efforts to treat the condition, it was not until the 1950s that advances in medical science, developments in antibiotics and neurosurgery, the introduction of the new shunt system by Holter, made active treatment productive. However, during that decade, since many infants still died of meningitis or other complications, a percentage only of the babies born each year with myelomeningocele received vigorous treatment. "Even in the most advanced neurosurgical centre in Boston," Lorber writes, "Ingraham and his colleagues (1944) operated on infants only if they had no serious neurological lesions and had survived for at least a year or 18 months from birth, and if their general condition was good" (p. 5).

While in Sheffield (Children's Hospital), the policy was introduced to treat more and more infants, and the results of this aggressive approach were felt around the world during the 50s-60s, selective treatment remained the general rule in some pediatric centers, as the reports of Hide (Oxford),² Stark and Drummond (Edinburgh),³ Smith and Smith (Melbourne),⁴ Shurtleff et al. (Seattle),⁵ Woolraich,⁶ Feetham,⁷ Robertson,⁸ all show. The natural history (the shunt-therapy, paralysis, mental retardation, bowel and bladder problems, the social, educational, marital implications), as described in Laurence's classic analysis, for instance, continued to deter the universal acceptance of a policy of automatically initiating aggressive care plans for all infants, pediatric advances notwithstanding.⁹

It is against this background that we should assess the selection and treatment policy at Oklahoma's Health Sciences Center. Before looking at the OUHSC team's criteria for vigorous and supportive care, honesty demands we acknowledge that the Center's policy lies within a stream of philosophy and practice that has both long history and respectable allies. Further, fairness also demands we admit that even R. B. Zachary, one of the pioneers of aggressive treatment, and the consistent critic of Lorber's approach, does not advocate that surgery be performed on every child with spina bifida. "It may be asked whether I would advocate operation on every baby with spina bifida," Zachary writes (*British Medical Journal* 1977:2: 1460-1462). "Of course not. As with every aspect of surgery, there are criteria for selection, which should be based on sound medical and surgical principles and a knowledge of the prospects with and without surgery." Babies, in Zachary's charge, with severe intracranial hemorrhage or another major life-threatening anomaly, for instance, would not receive surgery because it would have no bearing at all upon whether these infants lived or died. The traditional rule about futile treatment wisely applies.

The Criteria Issue

One distressing fact about the OUHSC published report is the repeated

admission that the myelomeningocele team reached its consensus decisions without precise clinical criteria for vigorous or simply supportive care. "Whereas there are no specific criteria for treatment, factors considered significant by Shurtleff et al (and to a lesser extent, those considered significant by Lorber) are reviewed. Usually a consensus is achieved, but sometimes the team is ambivalent. In this instance, a recommendation for treatment is made," runs the relevant section. Whether all the selection criteria proposed by Shurtleff in 1974 are considered decisive remains unclear, as does also why the specific factors Lorber presented are significant only "to a lesser extent." While the three case reports included in the study refer to "severe congenital hydrocephalus and an L-1 level of paralysis at birth," (the other two cases mention "congenital hydrocephalus and a large thoracolumbar sac" and a male infant with "a T-10 level of paralysis and congenital hydrocephalus at birth"), detailed reasons, charts and graphs are disappointingly missing. Exactly why supportive care was recommended for 33 babies (the major adverse clinical criteria) remains unclear.

Serious questions abound. "Why did they recommend only supportive care for these children (five children with L-5 sacral lesions)?" specialist John Freeman, Birth Defects Center, Johns Hopkins Hospital, asks.¹⁰ This lack of scientific rigor, the incomplete presentation of the degree of severity and incidence of complication that we find in Laurence, Lorber, Shurtleff, the reports of Smith and Smith, Hunt et al.,¹¹ and Sherman Stein, Schut and Ames,¹² as well as the failure to present all their working criteria, are hard to understand, and one well appreciates Freeman's strong comments, and the words of Nat Hentoff about "a death row for infants in Oklahoma."¹³ One hopes that the myelomeningocele team will publish its criteria for selection in full, together with its rationale for prioritizing, excluding and including clinical factors in its evaluations.

The Decision Making Issue

The OUHSC report does give information about key aspects of the team's approach: its method of making treatment decisions; the actual membership and structure of the team both in theory and practice. We are told something about the difficulties the team faced in combat. First, the team is made up of a physician's assistant, acting as full-time program coordinator, a pediatrician, an orthopedist, a neurosurgeon, a urologist, a nurse clinician, a social worker, physical and occupational therapists, and a psychologist. One of the physicians is chief of the program. Certainly, such a group possesses the range of medical knowledge and expertise not only to provide data for highly reliable recommendations, but also for efficient ones. Decisions, the report mentions, are made by consensus, and communicated to family by several members of the team as a group: "One physician accompanied by the coordinator, social worker, and/or nurse." Furthermore, regular contact with the family after it has elected to defer surgery, is maintained by the clinic coordinator and social worker.

In day-to-day life, however, this approach, structure and decision making method had real problems. "Usually a consensus is achieved, but sometimes the team is ambivalent," the report states. Also, we are told, "occasionally, a decision was made in what could be considered, in retrospect, an inadequate assessment." In the second case report, we are informed, "a rapid evaluation was made. Only two of the team members (which two?) saw the baby, and no input from Social Services was obtained." Most disconcerting, moreover, is the following: "with the number of diverse personnel involved, differences do occur in decision making and the approach is not uniform from one case to the next. However, the alternatives of a dogmatic protocol or an incomplete evaluation by less than all services involved appeared to us to be unsatisfactory choices" (p. 455).

John Freeman has severely criticized these admissions, the claims that the approach is "workable" and results in assessments that are "reasonably accurate." The admitted lack of uniformity is a major cause of concern, I concur. Although treatment decisions are often a mix of imperfect science and human art, any approach to them should embody maximum consistency, as little arbitrariness as professional responsibilities demand. A uniform approach to the treatment of spina bifida, AIDS or cancer need not imply either of the alternatives the report mentions. Moreover, in the actual contents of the negative recommendations, the report contains difficulties not mentioned by Freeman, which provide further cause for comment.

"If the team's assessment is pessimistic," the report states, "the family is informed that we do not consider them obligated to have the baby treated. They are given time to assess the information before they reach a decision" (p. 452). Surely, there is something wrong with this statement, especially the phrase, ". . . we do not consider them obligated to have the baby treated." Has a medical team the right to make such a recommendation? Is this a communication of a clinical evaluation and an agreed medical judgment or something different? Personally, I consider such a statement not only a serious usurpation of parental authority, but a classic example of medical paternalism at its worst. Parents should be assisted with their feelings of guilt, as Cohen advises.¹⁴ However, such support should not, I believe, distort the physician-patient roles.

The thrust, the implied control, furthermore, clearly undermines the team's stated belief that parents rather than the team's experts in the field of myelomeningoceles are the real decision-makers. The team acts, so the report states, upon the parents' decision. Aggressive treatment will be given should parents request or insist, in spite of a pessimistic assessment by the team, and presumably, supportive treatment will be given to a child when parents ask, in spite of an optimistic recommendation.¹⁵ Is this, whatever the nation's feeling about parent rights, a sound decision-making policy? John Lorber has written, "Who should make the decision to treat or not to treat? Most consider that it is the doctor's duty. The doctor should

be a consultant and an expert in this field of medicine (Ellis, 1974). Without such a proviso, disastrous mistakes may be committed. One cannot leave the decision to junior staff. One cannot leave it to the parents because they are hardly ever sufficiently informed and because they are under severe emotional strain at the time . . . Of course, the parents' wishes must be taken into account, though usually they will ask the doctor's advice, even if the doctor appears to leave the decision to them."¹⁶ As all who have viewed the educational video, "Born Dying" or assisted parents of spina bifida infants, should agree, there is wisdom in these words, even if they run counter to the stream of legal and medical inclinations in the US and Britain today.¹⁷

The Philosophical and Ethical Issues

The OUHSC report does not deal with basic philosophical issues, but rather with such matters as whether the team's program is workable, whether it addresses, in a reasonable fashion the current ethical dilemma concerning the treatment of spina bifida infants. However, often it implicitly deals with such issues as the purpose of medicine and the social responsibilities of health care professionals. Decisions not to treat aggressively reflect attitudes about life and death, the meaning and purpose of health and illness. Indirectly, at least to some degree, those who make such judgments are expressing convictions about society, authority, science and civilization. In making a decision about treatment, expressly not to treat a baby with an L-5 sacral lesion whom (it must be presumed) one knows to have the potential for "normal" if restricted life, given the advances which have taken place in special education, etc., during the 70s,¹⁸ do we not see definite signs of significant philosophical ideas at work? Nevertheless, since the team's report does not address such ideas specifically, all comments are hazardous, and best wait until the court proceedings or later team-publications. The moral aspects of this program and decision making, however, are expressly addressed.

The report considers the following: i) who should make the decision about treatment and upon what data base; ii) what is the soundness of Shaw's formulation of the quality of life, with its emphasis on the societal factors; iii) how should babies for whom only supportive care is recommended be cared for; iv) the compatibility of the team's approach with the thought of Jesuit ethicist, Richard A. McCormick. Nowhere — and it is rather surprising in the American context — does the report raise the issue of rights, or the responsibilities of communities toward members. Nowhere does this final section of the report discuss such matters as extraordinary or heroic measures in the context of spina bifida, the just distribution of medical/community resources, or this society's growing concern about hard cases in which the benefits are doubtful.

One cannot be involved with cancer, alcoholism or myelomeningocele without being aware of the financial, emotional, marital stress these

conditions impose upon spouses and families. To what degree, however, should the impact of such stress upon next-of-kin influence treatment decisions? Should our treatment of people with identical symptoms, age, general circumstances, be quite different depending upon their support-systems, whether a patient is a widow without children or married, 50, with strong family ties? For the OUHSC team, the home and society factors are crucial in any decision about vigorous or supportive care. Patently influenced by Anthony Shaw's controversial formulation of the quality of life ($QL = NE \times (H + S)$, where NE represents the patient's natural endowment, H stands for the contribution from home and family, S is the contribution from society), in spite of the strong criticisms of Paul Ramsey, among others, the report states, "The treatment for babies with identical 'selection criteria' could be quite different, depending on the contribution from home and society."¹⁹ Thus, an infant born to a black single-parent who is on ADC already, who comes from a country or state short of welfare funds, will be treated quite differently, one must assume, from a baby born to white, upper-middle-class parents who have medical insurance, strong family support, stable marriage and live in a state less hard hit by Reagan welfare cuts. While it is not hard to understand the reasoning and conclusion, something seems to be seriously faulty in this application of situation ethics.

The team's decision to build its moral basis upon the 1974 JAMA study, "To save or let die," by Richard McCormick, was unfortunate. In 1983, McCormick published another study in which he changed, clearly restricted the implications of some of his earlier views. McCormick's new position expressly sets limits on the use of his ideas as applied and implemented in centers like OUHSC.²⁰ In the first study we do find the principle presented as a primary guideline in decision making, namely, "the potential of the patient for human relationships." McCormick did state that if the potential is simply nonexistent "or would be utterly submerged and underdeveloped in the mere struggle to survive," that life can be considered as having achieved its potential and (one presumes), allowed to come to its end. Among his caveats, however, McCormick cautioned against using the principle like a slide rule, applying it from anencephalic to Down's babies.

In his 1983 study (published while the OUHSC report was awaiting its appearance in *Pediatrics*), McCormick visibly restricted the use of his principle. Life-saving interventions ought not to be omitted for managerial or institutional reasons, he states, or because of the inability of a particular family to cope with a badly disabled infant. "No one ought to be allowed to die," McCormick writes, "simply because these parents are not up to the task. At this point society has certain responsibilities.

A major limitation cited by McCormick is that life-sustaining interventions may not be omitted simply because the baby is retarded. Only where there is excessive hardship on the patient, especially when this is combined with poor prognosis, or when it becomes clear that expected

life can be had for a relatively short time and only with the use of continued artificial feeding, does McCormick see that intervention may be omitted. Further, throughout this study McCormick insists that the best interests of the infant are central, and outweigh all other considerations. The proper welfare of a baby should take precedence over the wishes and decisions of parents, and should provide society with a legitimate basis for direct intervention. In view of these firm statements, the OUHSC team's thinking can be considered as only *remotely* aligned with McCormick's approach and categorically contravenes his recent specifications.

Before moving to the legal aspects raised by this report, the fact the OUHSC myelomeningocele team recommended supportive treatment for 24 infants during the period July 1, 1977 - June 30, 1982, the following question must be asked, "As we look back at the ethical heritage of this Republic and study the moral philosophies respected in this society, what sound, intellectually satisfying reasons can be produced for maintaining that a baby born today with such adverse criteria as L-5 sacral lesion, hydrocephalus, other tell-tale signs of severe spina bifida — *not* major intracranial hemorrhage or obvious symptoms that death is imminent and impossible to prevent — should be allowed to die? Is it defensible to argue that it may be permitted to die since its life (spent at the age of 10, should it live that long, in a wheelchair, aided, perhaps by calipers, with any hydrocephalus controlled by a valve system etc., as Zachary writes in his "Life with Spina Bifida," *British Medical Journal*, 1977;2:1460-1462), is not worth living and it is better off in heaven? Is it right to allow it to die because its parents decide it should? Finally, is it ethically sound to justify such a death on the grounds that a pediatric specialist/team judges the parents to lack adequate financial, emotional or community support to provide properly for the infant, and determine it ought to be allowed to die from non-treatment?"

Such questions will always divide the health care community, especially when some give ultimate value to the overall good of their actions, while others stand with the growing number who hold rights: the right to live; the right to health care sufficient to protect that life; the right to access to health care for all, regardless of ability to pay; as ultimate principles in treatment decision making. In today's pluralistic society, when recommendations are made by team consensus as at OUHSC, a consulting pediatrician, faced with debate over reliable clinical criteria, parents opposed to aggressive treatment, plus the reality of a report from hospital social services that a mother lacks emotional maturity to deal well with her infant, may be justified in thinking he is dealing with a genuine dilemma. In reality the truly wise and most compassionate path — the moral course — may be less hard to decide.

In Nebraska, for example, Jack Trembath, spina bifida consultant, St. Joseph's Hospital, Creighton University and University of Nebraska Medical Center, Omaha, has little trouble in finding foster parents when an infant's natural parents are unwilling or unable to provide care. Jim

Miedaner, director of Physical Therapy, Meyer Children's Rehabilitation Institute, has strengthened an impressive program that maximizes mobility, independence, educational achievement.

With the technology now available, the antibiotics, the advances in physical therapy and special education (I refer especially to the 1985 report of Sherman *et al* and their eight-week program for teenagers with spina bifida which showed better than expected, outcomes in areas such as consolidating identity, achieving independence, establishing satisfying interpersonal relationships, finding a vocation), one wonders whether it is just and beneficent, the "good" thing in terms of the Hippocratic Oath, to recommend that an infant now born in Omaha with spina bifida (L-5 sacral lesion, etc., as described above) should receive simply passive treatment.

As the American Academy of Pediatrics Committee on Bioethics stated, ambiguities and differences of opinion should not preclude consensus on some ethical principles, in particular, the most basic of all for health care providers, namely, that one's primary obligation is to the child-patient, and that withholding or withdrawing life-sustaining treatment is justified only when such a course serves the interests of that child. We may not be able to accept that the actual limited potential of the child or the present lack of community resources are "irrelevant" in making treatment decisions (as the Joint Policy Statement of the Academy maintains), but we should be agreed that the infant's medical condition should be our focus throughout.

Hard cases, however, will be debated, forever, and certainly as the OUHSC case comes to trial. While an ethics report under the auspices of the Newcastle Regional Hospital Board concluded in 1975 that "the list of initial adverse criteria set out by Lorber, provides a sufficient basis for . . . selection," (the Lord Bishop of Durham and the president of Ushaw College were members of the working party) I seriously doubt whether our guardians and protectors of the weak, underprivileged, and less fortunate in this community ought to be moved by arguments, whether "quality of life" or "social benefit," which destroy or violate the Constitutional foundations and customs of this democracy.²¹ To borrow a line from Richard McCormick, any general guideline, any set of arguments which does not embody mercy and compassion for the neighbor in greatest need is nothing but a racism of the adult, the healthy, the fittest, and eventually a source of corrosion of the humanity and civilization of those who sit in courts and congresses.

The Legal Issue

According to Dennis J. Horan and Burke J. Balch, the debate over the respective roles and rights of the state and parents in decision-making about children has been long settled.²² "The state," they write, "in the exercise of its *parens patriae* power, has always had the authority to

intervene on behalf of the best interests of the child" (p. 45). The crux of the controversy is over the *best interests of a handicapped, a spina bifida child*, for example. In the judgment of Martin Gerry, HEW director of the Office for Civil Rights, 1975-77, the facts stated in the OUHSC report indicate a clear violation of state and federal law, of child-abuse statutes and criminal laws. "I think what you have here," writes Gerry, "is a conspiracy to commit murder."²³ If this legal opinion does have validity, then the court proceedings will be most significant. The central issues, however, will be hard fought.

First, there is the issue of whether children born with severe disabilities are protected under the 14th Amendment of the Constitution, especially if, as may be argued by the attorneys for OUHSC, they are "dying" or lack sufficient criteria or potential to be legally called "persons." On the adverse clinical criteria issue, the well-publicized opinion of Dr. David McLone, chief of pediatric neurosurgery, Chicago Children's Memorial Hospital, that physicians are making decisions not to treat aggressively on the basis of invalid criteria will have weight, as will comments like Freeman's about the OUHSC's day-to-day procedures for determining treatment decisions. On the other side, OUHSC's clinical criteria will be strongly defended, as will the argument that supportive treatment, when rightly determined, is in the best interests of the baby, as the editors of the *British Medical Journal* have argued more than once. The case will hinge on issues of fact; for instance, what were the crucial factors in the decisions about the 24 infants who did not receive vigorous treatment, who made the clinical assessments in these cases, what specific tests were completed, what do the records show about the severity of the spina bifida, and of course, the force of social and family factors in the recommendations against aggressive treatment. The legal aspects, the specific readings of state and federal statutes, may be less unclear now that Congress has settled its 1984 Child Abuse Prevention Act discussions.

Personally, it would appear from the report that the OUHSC team did fail to meet some standards of competence in making a number of their decisions about treatment. On its own admission, the team was greatly influenced in its final recommendations by Shaw's suspect quality of life equation. Whether the team was guilty of culpable negligence or violated the legal rights of infants in such instances can be decided only after all the facts and arguments have been presented. Whatever the final judgments, one hopes that justice not only will be done — to all involved — but will be seen to be done.²⁴

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