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THE PLIGHT OF THE GENETICALLY HANDICAPPED NEWBORN: A COMPARATIVE ANALYSIS

Confusion and controversy surround efforts to re-evaluate and, thus, redefine the extent to which governmental intrusion should be allowed in the doctor-patient relationship vis-a-vis the treatment or non-treatment of genetically handicapped, at risk infants. The purpose of this article is to present a succinct comparative analysis of the medico-legal posture in Britain and the United States and from this analysis to develop a construct to aid the physician and the family in making decisions concerning the administration or the withholding of treatment for genetically defective newborns.

1. The Influence of Federal Legislation in the U.S.A.

Over seven thousand hospitals in the United States receive federal funding for various parts of their administration. Failure to provide medical or surgical assistance to newly born infants with severe birth defects could well violate those civil rights conferred upon all citizens, and especially children, under the Federal Rehabilitation Act of 1973 as amended by the 1978 Rehabilitation, Comprehensive Service and Developmental Disabilities Act. The Act defines a handicapped individual as one who has either a physical or mental disability which in turn constitutes or results in a substantial handicap to employment and who has a physical or a mental impairment which limits substantially one or more of the major life activities. It specifically declares that no handicapped citizen of the United States, solely for reasons of a handicap, will "be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance....."

On March 22, 1983, in a subsequent federal regulatory scheme steps were taken to ensure that there be no discrimination against defective newborns: prominently displayed signs in maternity wards and in other parts of hospitals would announce a non-discriminatory policy for handicapped infants and a prohibition against the denial of good or customary medical care (which was not defined) was set in operation; anonymous tipsters were encouraged to call a "Handicapped Infant Hotline" at the United States Department of Health and Human Services in Washington, D.C., if they knew of any such acts of discrimination. When challenged, these regulations, dubbed by the popular press as the "Baby Doe" regulations, were voided by a federal court as being arbitrary and capricious.

"New" regulations, redrafted in light of this challenge, were submitted for public comment on July 5, 1983, and promulgated in final form on January 12, 1984. In essence, these rules declare that where medical care is clearly beneficial it should always be provided to a handicapped newborn. Although recognizing a presumption should always be in favor of treatment, reasonable medical judgments will be respected regarding treatment and nourishment so long as such decisions to forego or withhold are not made on the basis of present or anticipated physical or mental impairments. Thus, decisions not to commence futile treatment which would be of no medical benefit to the infant and which would present a risk of potential harm will be respected.
Infant Care Review Committees are encouraged, although not mandated, to be structured in the seven thousand health care institutions receiving federal financial assistance. These Committees will not only be charged with developing and recommending institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions, but will provide counsel in specific cases under present review. Adhering to various Principles approved by such groups as The American Academy of Pediatrics and The National Association of Children's Hospitals, the ICRC's will conduct their operations under the premise that where medical care is clearly beneficial, it should always be provided. Although recognizing that a presumption should always be indulged in favor of treatment according to the Principles, reasonable medical judgment will be respected regarding treatment and nourishment so long as decisions to forego or withhold are not made on the basis of present or anticipated physical or mental impairments. Presumably, the validity of the test of reasonableness will depend upon the facts of each case that arises.

Informational notices of the application of the Federal Law, posted where nurses and other medical professionals may view them, are required to include a statement of non-discrimination of health services (consistent with the specific provisions of section 504 of the Rehabilitation Act 1973) on the basis of handicap, of a size no smaller than five by seven inches, and list a twenty-four hour toll free "hot line" telephone number at the United States Department of Health and Human Services and/or state child protective services agency where violations of the Act may be reported.

Perhaps as important as the new Rules is an Appendix, "Guidelines Relating to Health Care for Handicapped Infants", which, while not independently establishing rules of conduct, are to be recognized as "interpretive guidelines" designed to assist in interpreting the application of Section 504. Considering Appendix C (a) (1) - (3) and C (a) (5) (ii) (iii) (iv), one finds a recognition that where any of the following situational standards operate no discrimination will be acknowledged and, thus, no federal intervention undertaken:

1. Where treatment would be futile according to reasonable medical judgment;

2. Where treatment would be unlikely to succeed given the complexity of the case; or otherwise would not be of medical benefit to the infant; or

3. Where it is recognized that a particular mode of treatment would probably not succeed or might cause harm.

It is interesting to observe that as of December 1, 1983, of the forty-nine cases of alleged discrimination in treatment of seriously handicapped newborns in federally assisted maternity wards, "no case resulted in a finding of discriminatory withholding of medical care."
2. The British Judicial Posture

The Sunday Times of December 4, 1983, carried an absorbing article concerning the plight of handicapped newborns in the United States and raised the question whether a similar condition could ever obtain in Britain. Only time, of course, can provide a definitive answer; but two important cases perhaps indicate a particular judicial attitude to the issue.

The first of these cases is *In Re. B (a minor)* which was decided in 1981. The facts showed that B, a female child, was born suffering not only from Down's syndrome but also an intestinal blockage and would require surgery in order to relieve the obstruction if she were to live for more than a few days. Although the surgery provided no guarantee of long life - in fact, there was a possibility that B might die within a few months - the evidence pointed to the fact that she could have an expectancy of normal mongol life anywhere from twenty to thirty years if the operation was successful. Her parents decided that in "the kindest interests of the child", no operation should be performed. Accordingly they advised the doctors of this decision and it was respected. The local authority thereupon made the infant a ward of the court and sought an order authorizing the operation be performed by other surgeons. The lower court respected the parental decision and refused to order the surgery. On appeal by the local authority, the Court of Appeal reversed that decision and held that parental wishes were secondary to what was in the best interests of the child. The parents argued that, owing to the fact that the child would be severely handicapped both mentally and physically, no evaluation of the quality of life of a mongoloid during its predicted short life span could be properly made. The Court determined that insofar as a "happy life" could be provided for a mongoloid, baby B was entitled to that life.

Noting that a judicial decision in a case of this nature requires the court to consider the child's interests as well as the views of the parents and their doctors, the court acknowledged that "at the end of the day it devolves on this court in this particular instance to decide whether the life of this child is so awful that in effect the child must be condemned to die, or whether the life of this child is so imponderable that it would be wrong for her to be condemned to die". The court continued, stating, that "There may be cases, I know not, of severe proved damages where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion".

Of interest also is *Regina v Arthur*, an unreported case decided at the Leicester Crown Court on November 5, 1981 three months after the *In re B* decision. Here, a mongoloid was born on June 28, 1980, and thereupon rejected by his parents. The consultant pediatrician, Dr. Leonard Arthur, prescribed "nursing care only" (i.e. a regime which included no food) for the child and prescribed regular doses of the drug DF118 for purposes of sedation. Originally Dr. Arthur was charged with murder, but during the course of the trial the charge was reduced to attempted murder. The doctor was subsequently acquitted by the jury. In his summation, the Judge referred to *In re B* and indicated that it was lawful to treat a baby with a sedating drug and to offer no further care by way of food or drugs or surgery provided two criteria were met: that the child is
"irreversibly disabled" and that it is rejected by its parents. Thus, the Arthur case seems to suggest the issue of treatment of a severely handicapped newborn child is a private matter between physician and parent and it is doubtful whether this verdict can be reconciled with In Re B. While it is clear the Arthur verdict does not legitimize the use of drugs in order to accelerate death, it is unclear whether it establishes the legality of a policy of nontreatment or whether "holding procedures" are valid in all cases.

3. The American Judicial Posture

Baby Jane Doe was born on Long Island, New York, on October 11, 1983, with spina bifida and an abnormally small head which was swelling with excess fluid. After consultation with physicians and members of the clergy, her parents refused to allow corrective surgery. If successful, the operation might have allowed the infant to live some twenty years but in a state of retardation, constant pain, an epileptic, and paralyzed below the waist.

The highest court in the State, the Court of Appeals, decided that the parents' decision must be respected. It refused to articulate the circumstances which would trigger judicial protection of an infant of this type merely observing that there may be occasions where it would be appropriate to intervene. Rather, it noted that the Legislature had designed a statutory scheme designed specifically for protecting children from abuse and, at the same time safeguarding familial privacy and relationships and that this procedure would be adhered to unless the Legislature, again, decided to amend the process.

Although refusing to deal directly with the need to establish criteria for validating decision making in cases of this nature, a key lower court decision in New York had indicated that only if there is a "reasonable chance" to lead a fulfilling and useful life, parental inaction regarding needed surgical intervention will not be permitted.

The very first Baby Doe case to be found and popularized by the press, involved a six pound baby boy born with Down's syndrome in Bloomington, Indiana, in 1982 who lived but six days. His death precipitated a national re-thinking of issues of infanticide, parental decision-making and power under the Common Law to exercise jurisdiction over the care of children and perhaps the most central issue of all: whether quality of life standards are more significant and fundamental than principles of sanctity of life. In addition to being born a mongoloid, with consequent mental retardation, "Baby Doe" (as he was dubbed by the press) had a malformed esophagus together with multiple physical problems. The esophageal condition prevented food from reaching the stomach. Rather than authorize corrective surgery, the parents chose to authorize a withholding of food and medical treatment, save pain killers, from their son. The Monroe County Circuit Court issued two orders preventing interference with the parental decision. These were upheld by the Supreme Court of Indiana. Before an emergency appeal could be taken to the Supreme Court of the U.S.A., Baby Doe died.

The English Court of Appeal precedent and the United States cases suggest a principle of "substituted judgment". Thus, the Court will seek to place itself in the position of the infant in extremis and determine whether, given its medical condition, it would wish to live under present or altered conditions - and whether a
meaningful or qualitative life could be achieved. Inherent in the
effectiveness of application of such a principle is the employment of a
cost-benefit analysis or balancing test. Stated simply, the costs
(social, economic) of maintaining life are weighed against the benefits
(religious, ethical, spiritual, etc.) of preserving it.

4. Seeking a Classification

The underlying principle of application should be to minimize
suffering and maximize the qualitative potential for fulfilling human
relationships and thereby promoting a purposeful life for the infant at
risk. The application of this principle, depends solely upon the
facts of each situation as it arises. To have an unyielding a priori
standard of mandated care for all seriously handicapped newborns would
be unjust for the infant itself, and would cause undue suffering. It
would be equally unjust and harsh for its parents and it would present
an unreasonably heavy burden to society in terms of use of scarce
medical resources. Efforts must be made to ensure, however, that if a
class is structured and labeled, "disabled", it is drawn as narrowly as
possible and as strictly defined as possible. Thus, the overriding
issue, then, is whether a construct can in fact be designed in such a
manner as to assist the supervising physicians, the family and their
religious counsellors and the state (when involved) in defining the
parameters of a class of nonsalvageable defective newborns?

At various times it has been suggested that the capacity for
consciousness, social interaction, human relationships (and especially
love) and rational thought were the four most important considerations
in determining who was to be placed in the "non-salvageable" classific-
aton. The importance of each capacity in the heirarchy of the class-
ification depends, very obviously, upon one's particular social, ethical,
religious and philosophical perspective. One leading ethicist has
stated that, "... the warmth of human interaction, the love of one person
for another, the emotional bonding that links people in moral communities
does not require a capacity for consciousness".

What is crucial in assessing these various capacities, no matter
which would be regarded as more important by a philosopher-ethicist, is
the actual physical condition of the handicapped newborn. If some
consensus could be reached that certain genetic afflictions are not
correctable by surgery or medical treatment in a way which would promote
a valuable life free of intense pain and suffering, then better, more
informed decision-making could be considered by the family and its
expanded circle, aided by the medical recognition or determination that
the at risk infant was one member of a classification for whom it would
be inhumane to sustain life.

The most constructive attempt to develop a classification or construct
may be found in the results of a study undertaken at Children's Hospital
in Sheffield, England, in the early 1970's where a list of six defects
were found and agreed upon as being of such a nature as to preclude the
possibility of an independent, dignified life or one in which meaningful
interpersonal relations could be enjoyed. They are:

1. Thoracolumbar or thoracolumbosacral lesion.
2. Gross paralysis with a neurologic segmental level at L3.
3. Kyphosis or scoliosis,
4. Gross hydrocephalus with a head circumference at least 2 cm above the 90th percentile related to birth weight.
5. Other gross congenital defects, such as cyanotic heart disease.

Conclusions

Child protection laws are, of course necessary. Their design and promulgation by the government are crucial if standards of equal protection for all its citizens, regardless of age or physical stature, are to be assured. It is a dangerously thin line to tread between familial privacy in decision making matters and government intervention. The judiciary, when called upon to evaluate cases of alleged abuse of handicapped newborns, can be aided by a close working partnership with the medical profession in seeking to decide when the withholding of needed medical or surgical treatment would be in the infant's best interests, and in the interest of others immediately concerned. This is a proper object of judicial inquiry. The classification for decision making proposed herein is of value not only to the courts, but also to the parents of a handicapped infant who, themselves, must confront the initial decision regarding sanctified qualitative living. Given the medically agreed upon components of this modest construct, and the laws already in place protecting children from abuse, there is no need for direct government involvement or intrusion into the sensitive area of familial autonomy by way of statutory regulatory schemes like the one presently in operation in the U.S.A.

Postscript

Because of judicial uncertainty in defining with clarity the role of health care providers and of parents in dealing with handicapped at risk newborns, the United States Congress sought to amend during its 98th session, provisions of The Child Abuse Prevention and Treatment Act and the Adoption Reform Act of 1978. The reform was designed to make the withholding of medical treatment from handicapped babies with life threatening conditions the basis for an action of child neglect and abuse at the state level. The Act was subsequently passed and signed into law on October 9, 1984, by President Reagan and entitled, "The Child Abuse Amendments of 1984". The Secretary of Health and Human Services promulgated new regulations designed to implement this law on December 10, 1984.

While the basic policy of these model guidelines is to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions, the guidelines specifically do not apply and thus, do not mandate a course of treatment, where a physician's reasonable judgment is that: the infant is chronically and irreversibly comatose; where treatment would merely prolong death; not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant or — finally — such treatment would be "virtually futile in terms of the survival of the infant and the treatment itself under such circumstances [which] would be inhumane".
Only time will provide the ultimate test of whether this scheme will be accepted by the American courts or challenged as an unwarranted intrusion into familial decision-making. It can be but hoped that a final chapter can be written and acknowledged by all elements of society soon and thus provide a final conclusion to a painful dilemma for the parents of handicapped at risk newborns and their attending physicians.

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4. Id. at Sec. 706(7) (A).  
5. Id. at Sec. 706(7) (B).  
   Section 504 of The Rehabilitation Act has been codified as Sec. 794.  
7. 48 Federal Register 9630 at 9631, 9632 (Mar. 7, 1983).  
8. Am. Academy of Pediatrics, et al. v. Margaret M. Heckler, Sec.,  
Dept. of health & Human Services, April 14, 1983, 51 United States  
Law Week 2628 (April 26, 1983).  
9. 48 Federal Register 304-52 (July 5, 1983).  
10. 49 Federal Register 1622.  
11. Id. at 1652.  
12. Id.  
13. Id. at 1653-1654.  
14. Id. at 1652.  
15. Id.  
16. Id. at 1652.  
17. Id.  
18. Id. at 1651.
19. Id. at 1653-1654.
20. Id.
21. Id. at 1646-1649.
24. Id., at p. 1422.
25. Id., at p. 1423.
26. Id., at p. 1424.
29. Glover, Letting People Die, 4 London Rev. of Books 3 (Mar 4-17, 1982).
34. G. Smith, Genetics, Ethics and the Law 2, 8 (1981).
35. Supra note 28 at 15.

39. *Id.* at 245.

40. Lorber, Early Results of Selective Treatment of Spina Bifida Cystica, 4 Br. Med. J. 201 at 204 (1973). It was suggested recently in the New England Journal of Medicine that termination of a pregnancy during the third trimester (or 25th week) could be normally justifiable when two conditions are fulfilled. Given a prospective mother's permission, the conditions are that: (1) the fetus is afflicted with a condition that is either a. incompatible with postnatal survival for more than a few weeks or b. characterized by the total or virtual absence of cognitive functions and (2) highly reliable diagnostic procedures are available for determining prenatally that the fetus fulfills either condition 1a or 1b. Anencephaly, or the marked defective development of the brain, together with the absence of the bones of the cranial vault clearly fulfills both conditions. Chervenak, Farley, Walters, Robbins & Mahoney, 'When is Termination of Pregnancy During the Third Trimester Morally Justifiable?' 310 New Eng. J. Med. 501 (Feb. 23, 1984).

41. Dickens, supra, note 27.

42. Burger, 'Reflections on Law and Experimental Medicine' at 211 in 1 Ethical, Legal and Social Challenges to a Brave New World (G. Smith, ed. 1982).

43. See e.g. in England, The Child Care Act, 1980; Children Act, 1975; Children and Young Persons Act, 1963; Children and Young Persons Act, 1933; and the Infant Life (Preservation) Act, 1929.

44. 42 United States Code, §5101 (a) et. seq. (1978).

45. H. R. 1904, S. 1003.


47. 49 Federal Register 48170 (Dec. 10, 1984).

48. *Id.* at 48171.