

May 1977

Redefining the Issues in Fetal Experimentation

Eugene F. Diamond

Follow this and additional works at: <https://epublications.marquette.edu/lnq>

Recommended Citation

Diamond, Eugene F. (1977) "Redefining the Issues in Fetal Experimentation," *The Linacre Quarterly*: Vol. 44 : No. 2 , Article 15.
Available at: <https://epublications.marquette.edu/lnq/vol44/iss2/15>

Redefining the Issues in Fetal Experimentation*

Eugene F. Diamond, M.D.

Doctor Diamond, a member of the department of pediatrics at Loyola University's Stritch School of Medicine, is also an associate editor of Linacre Quarterly.

There has been a crisis of public confidence (*Marriage and Family Newsletter*, January 1972, pp. 1-8) in the medical profession generated in this country by the performance of vivisection-type experiments on live aborted fetuses¹ and highly questionable therapeutic trials involving institutionalized mentally defective children.^{2,3} Very few investigators and a small number of studies are involved. Measures to prevent a recurrence of abuses are appropriate, but the response of the medical profession to attempts to establish guidelines has been hyperbolic, and overblown, and inconsistent with the profession's crucial responsibility to patient advocacy.

The issue has never been *whether* research would be conducted but *how* it would be conducted. Research is not necessarily deterred by restrictive guidelines. It is quite possible that research as a whole would be advanced if the public were reassured that no further abuses would be tolerated (*News & Comment* 25:8, 1974).

Much of what has been indignantly defended in the medical literature as "essential to progress" was never at issue in the debate. Responsible opponents of inappropriate fetal experimentation have not opposed the taking of fetal blood samples in amounts that were not exsanguinating or a threat to circulatory function. Similarly, the aspiration of amniotic fluid specimens, the majority of which would be done for therapeutic indications, would not be precluded by most state laws as proposed. The proposed Illinois law would specifically exempt procedures done to establish cell-culture lines, providing that these procedures were not, of themselves, life-threatening (HB-2211 78th General Assembly, State of Illinois). Almost all guidelines specifically indicate that experiments done to promote the health or preserve the life of the experimental subject were not to be forbidden.

Questions of Consent

The systematic performance of abortions in order to make

*Reprinted with permission from *The Journal of the American Medical Association*, July 19, 1976, Vol. 236, No. 3, pp. 281-283. Copyright 1976, American Medical Association.

fetal donor organs available for transplantation would not be tolerated (*J Religious Ethics* 2:33, 1974). However, the occasional use of fetal organs, such as the thymus, for transplantation would not be routinely opposed, providing that the aborted infant were dead, using the same criteria for death determination that would be applied to an adult donor. One need not approve of abortion in order to allow the disposal of the tissues of the child who is dead as a result of abortion. One need not approve of murder in order to allow the murder victim's body to be autopsied or his organs to be donated (*Natl Right to Life News*, September 1974, pp. 10-11). Criteria such as those of the Ad Hoc Committee of the Harvard Medical School⁴ could be used to establish that the aborted child was, in fact, dead before organs were removed for transplant. Likewise, the criteria of the Uniform Anatomical Gift Act could be applied to the use of body parts of deceased infants, subject to the approval of next of kin.

Whereas next of kin might reasonably qualify to grant autopsy permission, there is serious question as to whether the mother who has consented to abortion would qualify to give permission for nonbeneficial research on her aborted child. If the decision to abort is accepted as a resolution of a conflict between the rights of the mother and the rights of the child, then it must be admitted that the

mother who chooses abortion has demonstrated her willingness to prefer her rights to those of the child. This would be the case in all instances except the very rare situation where no abortion means death for both the mother and fetus. Arguments that are proposed under the rubric of the "woman's right to her body" usually unscientifically and erroneously define the fetus as a *part of* the woman's body rather than a *resident in* the woman's body. In either event, no such claim can be made by the woman for control over an infant placed *outside* of the woman's body by an abortion procedure.

In hearings before the Health Subcommittee on the subject of fetal experimentation, Senator Edward Kennedy suggested⁵ that it would be hard to justify to reasonable men and women the proposition that the mother of an aborted infant had "the interest, love, and concern for the patient foremost in her mind when she gives consent to experimentation on her live aborted offspring." Parents who give proxy consent to experimentation on their children are usually accepted as having such affectional bonds to the child outside of the context of abortion, but the assumption of such loving interest is highly questionable when experimentation on aborted subjects is at issue.

This is of particular importance when the experiment proposed is nontherapeutic in nature. It is, in fact, currently a

moot issue to be decided by the courts. (*Nielson vs Regents of the University of California, et al*) as to whether *any* parents may *ever* give consent to nonbeneficial research on a child. The aforementioned court decision may resolve the issue, but in the meanwhile, we may rely on a tradition traceable to English common law that a parent may not consent to anything that *injures* his child.⁶ This tradition is the basis for all child-abuse laws. No one may sign a permit for an illegal act on another person, even if that person is his own minor dependent child. A parent may require his own child's services but may not sell his child into involuntary servitude to another outside the family. The decision as to what constitutes legal proxy consent to nontherapeutic experimentation is likely to remain with the courts irrespective of any medical body's decision.

Questions of Viability

The World Health Organization defines a live birth as the delivery of a neonate with a heartbeat, a pulsating cord, a muscular movement, or a respiratory effort. A crucial difference between the opposing camps in the fetal experimentation debate revolves around the right to protection of the *live-born* product of an induced abortion. One camp concentrates on the fact that the infant is, in fact, now alive. The other camp concentrates on the fact that he is *nonviable* by prognosis. Opposition to nontherapeutic experimentation on such

an infant is based on the principle that no experiment can be justified merely on the basis of the fact that the patient suffers from a uniformly fatal disease with a short life expectancy. This rule would have as much validity if the abortion had been spontaneous rather than induced.

It would be preferable to separate the issues of fetal experimentation from the emotionally charged issue of abortion. The Supreme Court decision of Jan. 22, 1973, while it has called into question the rights of the pre-viable fetus in utero, has not affected the rights of any live-born infant once he is outside the womb. Some investigators, however, seem to have inferred otherwise and have specifically referred to the aforesaid abortion decision as a justification for experimentation. The Society for Developmental Biology, for example, has stated in a unanimously approved resolution that it "supports the continued use of human tissues at all states of development, embryonic and fetal, within the framework of the *Doe vs. Bolton* ruling of the U.S. Supreme Court" (*Pediatric News*, September 1975, p. 5). John Opitz, MD, at the Annual National Foundation Birth Defects Conference, is quoted as follows: "The Supreme Court decision on abortion defined the right of every citizen to make an informed decision on abortion. This right must not be abridged by restrictions on fetal research" (*Pediatric News*, September

1974, p. 7). It would seem that it is the proabortionists, not the anti-abortionists, who have confused the issues of abortion and experimentation. A careful reading of *Roe vs Wade* and *Doe vs Bolton* would support the notion that its principles cease to apply once the mother is separated from her offspring. The Supreme Court was reluctant to confer "personhood" prior to birth, but it is difficult to see how it could avoid conferring personhood on a living, albeit previable, infant. Surely the infant cannot be construed as a part of the mother, with its rights in conflict with hers, if the mother is in a recovery room and the infant is in an incubator in the nursery.

Extrinsic vs Intrinsic Value

As in the abortion debate, there has been an unfortunate attempt to inject religious issues into the debate by absurd slogans such as "Know-Nothingism" (*Hospital Practice* 9:11, 1974) or dark references to the Galileo trial or the Scopes case.⁷ The medical profession, in consigning the protesters to the peculiar isolation of a lunatic fringe, does so at the peril of its own political credibility. The entire spectrum of the society is very literally involved in this debate. The original protests against the Willowbrook experiments originated on one end of the political spectrum from the Student Health Organization at Mount Sinai (*Contraindications* 2:1-4, 1974) and the original protests against fetal experimentation originated from a

small band of high-school protesters from a convent school in Maryland (*Pediatric News*, May 1973, p. 1) on the other end of the spectrum. The issues are non-sectarian, but they do contrast two philosophical positions. One position would assert a transcendental view of human life at all stages of life's continuum, embryonic, fetal, child, adult. Life at all stages, in this view, has an intrinsic and unquantifiable value. This value transcends the real or alleged values of experimentation and research. If a human being is deformed, dying of a fatal disease, or previable, the ontological goodness of his being is still intact.

The other position would consign to human beings values that are extrinsic. Each human life is not an end in and of itself, but rather a means to another end, which is the good society. Extrinsic value is not a per se condition of life, and some are said to lack it.⁸ From the totalitarian view that the individual exists for the society, one can conclude that experiments can be performed on a member of this generation in order to assist members of future generations. A small injustice to this previable infant may result in great benefits to mankind. An experiment performed on a pregnant woman scheduled for abortion may help a "wanted" child to have a better chance of survival. Lives which grossly lack "quality" (e.g., trisomy 21) should be terminated early for their own and society's good.⁹

As Rabbi Immanuel Jakobovits¹⁰ has pointed out, however, if one life is construed as having infinite value, then one life is as valuable as many lives, and any small fraction of a life has infinite value because any fraction of infinity is still infinite.

Fetus ex Utero vs Infant

How can these two conflicting views be reconciled in order to establish guidelines acceptable to both philosophies? One essential first step is to treat the live-born pre-viable child delivered by abortion the same as any other subject for human experimentation. The proposed policy of the Department of Health, Education, and Welfare¹¹ on Protection of Human Subjects displays some reluctance to do this.

For example, the commission lists four principles that it describes as "among the general principles for research judged to be valid and binding." The second of these four principles (referred to as the "principle of equality") is as follows: "To provide for fair treatment by avoiding discrimination between classes or among members of the same class." Commenting on this principle of equality, the commission anticipates that "differences of interpretation will arise over the application of the basic principles of equality and the determination of minimal risk." The report explains, "Some members held that no procedures should be applied to a fetus to be aborted that would not be applied to a fetus going to term."

This proposal was rejected, however, and the protection afforded the not-to-be-aborted fetus in recommendation 4 is effectively removed from the fetus in anticipation of abortion in recommendation 5 by the proviso that a "national ethical review body" might allow nontherapeutic experiments of greater-than-minimal risk to the fetus to be aborted. Louisell,² in his minority report, recommends that this provision be eliminated in favor of a declaration that "no research should be permitted on a fetus to be aborted that could not be permitted on one to go to term."

Likewise, in its recommendation 6, the commission provides for the possibility that, with maternal approval and lack of paternal objection, certain infants up to five months gestational age might be submitted to nontherapeutic research not possible on other live human beings, providing again that a "national ethical review body" approves. Interestingly, such a subject for experimentation is described as a "non-viable fetus ex-utero." Traditionally, medicine, law, and the society in general have used the term "human infant" to describe a live birth regardless of its degree of prematurity. In its recommendation 7, the commission itself refers to the "possible viable *infant*" rather than the "possible viable *fetus ex-utero*" and then proceeds to accord to this "infant" protections not accorded to the class described as

"fetuses ex-utero" by the elimination of the "review body" escape clause. Since "fetus" is a word used to describe a stage of *intrauterine* life, "fetus ex-utero" is probably a contradiction in terms that, one may reasonably suspect, was chosen to reflect an unwillingness to humanize the pre-viable infant (particularly when it was born as a result of induced abortion). The sophisticated classification used by the commission is very helpful in structuring the discussion. It must not be accepted as a means for defining some human beings out of existence, however, nor a means to divert our attention from what our experiment proposes to do and onto the nature of the experimental subject.

Once the "non-viable fetus ex-utero" is treated as a small human being while alive, many of the difficulties are reconciled. Guidelines based on this presumption can be developed, or the traditional guidelines of the Declaration of Helsinki or the Nuremberg Code can be applied to the model of research on the so-called "abortus." Article III-1 of the Declaration of Helsinki states: "In the purely scientific application of clinical research carried out on a human being, it is the duty of the doctor to remain the protector of the life and health of that person on whom clinical research is being carried out." This article would clearly preclude such experiments as those in which live-born fetuses were decapitated in order

that their heads could be perfused to study carbohydrate metabolism.¹ Articles I-3, III-3b, and III-4b would also be germane to the types of newborn experiments that have brought criticism (*Marriage and Family Newsletter*, January 1972, pp. 1-8).

Logical Inconsistencies

There are those who suggest that there is no way to understand the problems unique to prenatal and neonatal life without using experimental subjects during these particular stages. The same could be said of diseases peculiar to the geriatric age group or adolescence or any other age-specific disease process. This may not be used as a justification for suspending the rules on nontherapeutic experimentation or for settling down age-specific rules for obtaining consent (*Medical World News*, October 1973, pp. 32-36). Likewise, the limitations in translating animal data to human application are equally applicable to research done on human beings at all ages. In point of fact, progeny studies done on animal species have been successful in many instances in predicting adverse human effects of drugs. In the case of thalidomide, research done on almost every species of animal has demonstrated the production of limb-bud anomalies directly comparable to those produced in human subjects (*Medical Tribune* 72:3, 1966).

If the patterns of funding by the National Institutes of Health

are to be used as an indication, the performance of nontherapeutic experimentation on fetuses *in utero* and live-born aborted infants make up only a fractional part of the total of perinatal research. The unethical use of aborted experimental subjects is attributable to an infinitesimal percentage of researchers in this field. The establishment of reasonable controls over fetal experimentation need not pose a threat either to medical progress or to the responsible investigator.

Nonproprietary Name
and Trademark of Drug

Thalidomide — *Kevadon*.

REFERENCES

1. Adam PAJ, Raiha N., Rohiala E, et al: Cerebral oxidation of glucose and D-beta hydroxy butyrate in the isolated perfused human head. *Trans Am Pediatr Soc* 309:81, 1973.
2. Goldby S: Experiments at Willowbrook State School. *Lancet* 2:749, 1971.
3. Krugman S: Experiments at Willowbrook State School. *Lancet* 2:966, 1971.
4. Report of the ad hoc committee of the Harvard Medical School to examine the definition of brain death. *JAMA* 205:85-88, 1968.
5. Hearings of the health subcommittee of the senate labor and public welfare committee. *Congressional Record* S11776-11785, June 27, 1974.
6. Pappworth MD: *Human Guinea Pigs: Experimentation of Man*. Boston, Beacon Press, 1967, p. 31.
7. Dykes MHM, Czapek EE: Regulations and legislation concerning abortion research. *JAMA* 229:1303-1304, 1974.
8. Fletcher J: Indications of humanhood: A tentative profile of man. *Hastings Center Rep* 2:1-4, 1972.
9. Shaw A: Dilemmas of "informed consent" in children. *N Engl J Med* 289:885-890, 1973.
10. Jakobovits I: *Medical Experimentation on Humans in Jewish Law*. New York, Association of Orthodox Jewish Scientists, 1966, pp. 1-7.
11. Protection of human subjects: Proposed policy. *Fed Register* 40:33525-33534, 1975.

Are You Moving?

If the next issue of this journal should be delivered to a different address, please advise AT ONCE. The return postage and cost of remailing this publication is becoming more and more costly. Your cooperation in keeping us up-to-date with your address will be most helpful.