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AMNIOCENTESIS AND THE APOTHEOSIS OF HUMAN QUALITY CONTROL

Jacqueline M. Nolan-Haley, J.D., LL.M.*

INTRODUCTION

Five years ago I wrote of what I perceived to be the gradual metamorphosis of the value of life ethic in favor of a quality of life ethic.¹ The former attaches value to all human life if for no other reason than it is human. The latter ethic determines first what is human and then applies a value to it.

What prompted my consideration of this issue was an announcement by two Yale physicians that forty-three infants had been allowed to die at Yale-New Haven Hospital after a joint decision by parents and physicians that "prognosis for meaningful life was poor or hopeless."² My concern was twofold: would such decisions be restricted to the newborn nursery; and, who would be the ultimate arbiter of "meaningful life"?

During the past five years the quality of life ethic has continued to displace the traditional ethic. Due to advances in genetics, particularly the pre-natal diagnostic technique of amniocentesis, and the revival of the eugenics movement,³ the concept of "meaningful life" has assumed added dimension *in utero*.

The reasons offered by women who undergo amniocentesis vary

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¹ Nolan-Haley, *Defective Children, Their Parents and the Death Decision*, J. LEGAL MED., Jan., 1976, at 9.

² Duff, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED., 890 (1973).

³ See generally T. HOWARD & J. RIFKIN, WHO SHOULD PLAY GOD? (1977). See also Sammons, *Ethical Issues in Genetic Intervention*, 23 SOC. WORK 237, 240 (1978).

from a desire to know if a child has a genetic defect, an interest in learning the child's sex or simply the desire to have a beautiful baby.⁴ Prenatal detection of defects followed by abortion of those deemed "defective" has reduced the number of death decisions being made in newborn nurseries.

Under a quality of life ethic this is perceived as a "good." It spares parents the agony of making life/death decisions of the Yale-New Haven Hospital type and it fulfills what one physician has referred to as the societal interest in assuring only quality products.⁵ Under a value of life ethic, however, this mode of behavior is unacceptable. A New Jersey court has articulated the concern:

A child need not be perfect to have a worthwhile life ... The sanctity of the single human life is the decisive factor in this suit in tort. Eugenic considerations are not controlling. We are not here talking about the breeding of prize cattle.⁶

Under either ethic the question remains whether we are talking about and indeed encouraging the breeding of prize cattle. This article focuses upon the question in the context of consideration of amniocentesis and its significance for the legal and medical community.

I. AMNIOCENTESIS

The most prevalent method of genetic screening is amniocentesis, a pre-natal diagnostic technique which, when combined with abortion, provides the greatest guarantee of a quality child that physicians can accommodate in this age of consumerism.⁷ It does not follow, however, that normal results subsequent to performance of amniocentesis assure that a child is without malformations.⁸ While amniocentesis has been

⁴ Golbus, Conte, Schneider & Epstein, *Intrauterine Diagnosis of Genetic Defects: Results, Problems, and Follow-Up of One Hundred Cases in a Prenatal Genetic Detection Center*, 118 AM. J. OBST. & GYN. 897 (1974). See also Brody, *How Doctors Can Assure More Perfect Babies*, WOMAN'S DAY, Feb., 1977, at 65.

⁵ Morrison, *Implications of Prenatal Diagnosis for the Quality of, and Right to, Human Life: Society as Standard*, in ETHICAL ISSUES IN HUMAN GENETICS: GENETIC COUNSELING AND THE USE OF GENETIC KNOWLEDGE 201-211 (B. Hilton, ed., 1973).

⁶ *Gleitman v. Cosgrove*, 49 N.J. 22, 30, 227 A.2d 689, 693 (1967), *rev'd in part*, *Berman v. Allen*, 80 N.J. 421, 404 A.2d 8 (1979).

⁷ Sammons, *supra* note 3, at 238. Other methods of genetic screening are ultrasonography, radiography and fetoscopy, maternal blood and urine sampling. Goodner, *Prenatal Genetic Diagnosis: Present and Future*, 19 CLIN. OBST. & GYN. 965-76 (1976).

⁸ Editorial, *Prenatal Diagnosis of Downs Syndrome*, 242 J.A.M.A. 2326 (1979).

praised as a weapon of preventive medicine, the panegyrics may be premature.⁹ Few detected diseases can be treated or cured *in* or *ex utero* and second trimester abortion is generally the single "cure" for defects which are diagnosed.¹⁰ Since most physicians agree that there is no point in administering the test unless patients are willing to abort,¹¹ it may be preventive medicine only in the sense of the biblical mandate — if the eye is an occasion of sin, pluck it out.

Amniocentesis was developed initially to diagnose and manage cases of RH incompatibility.¹² At the present time it can determine fetal sex and detect a varied assortment of chromosomal conditions and metabolic diseases. It is generally recommended by some physicians for pregnancies where there is advanced maternal age or a family history of Down's Syndrome, although it is reported that the majority of infants with Down's Syndrome are now born to women less than thirty-five years of age.¹³ Amniocentesis is also recommended where there is a family history of spina bifida or muscular dystrophy, mental retardation in close relatives, Eastern European ancestry for Tay-Sachs disease and dispositive carrier status for sickle cell trait.¹⁴

The most recent use of large-scale amniocentesis has been in connection with prenatal screening and the diagnosis of neural tube defects which are among the most common major congenital defects in the United States. Detection of neural tube defects results from a five part testing procedure which culminates in amniocentesis.¹⁵

The process of amniocentesis involves examination of amniotic fluid to determine the extent of the presence of alpha-fetoprotein, a protein which is produced by the child while developing *in utero*. It appears in the amniotic fluid at increasing levels during the first fourteen weeks of pregnancy and after that time the level declines. Alpha-fetoprotein (AFP) is also found in the mother's blood. Research has shown that by

⁹ Culletin, *Amniocentesis: HEW Backs Test for Prenatal Diagnosis of Disease*, 190 SCIENCE 537, 540 (1975).

¹⁰ Milunsky, *Pre-Natal Diagnosis of Genetic Disorders*, 70 AM. J. MED. 7, 8 (1981); Luy, *Genetic Detection—The Newest Use of Amniocentesis*, MOD. MED., Sept. 2, 1974, at 31, 36.

¹¹ See, e.g., Chapman, *What Are Your Odds in the Prenatal Gamble?* LEGAL ASPECTS OF MEDICAL PRACTICE, March, 1979, at 30, 33.

¹² *Id.*, at 32.

¹³ Holmes, *Genetic Counseling for the Older Woman*, 298 NEW ENG. J. MED. 1419-21 (1978).

¹⁴ *Antenatal Diagnosis: What Is Standard?* 241 J.A.M.A. 1666, 1667 (1979).

¹⁵ *Maternal Serum Alpha-Fetoprotein: Issues in the Prenatal Screening and Diagnosis of Neural Tube Defects*, in PROCEEDINGS OF A CONFERENCE HELD BY THE NATIONAL CENTER FOR HEALTH CARE TECHNOLOGY AND THE FOOD AND DRUG ADMINISTRATION, in Washington, D.C. (July 28-30, 1980), at pp. 1-20.

measuring the levels of AFP in amniotic fluid it is possible to detect neural tube defects.¹⁶ However, not all neural tube defects can be diagnosed. High AFP levels may occur on a statistical basis or may represent an anomaly other than neural tube defects.¹⁷

The Food and Drug Administration has received several applications for premarket approval of AFP test kits which are defined by the FDA as "reagents and other materials for use in the diagnosis of neural tube defects in fetuses by analysis of the amount of alpha-fetoprotein (AFP) in the blood serum (or plasma) and amniotic fluid of pregnant women."¹⁸ Since these kits were not marketed commercially in the United States before the Medical Device Amendments Act of 1976 was enacted, they are included as a class III device under the Food, Drug and Cosmetic Act¹⁹ and therefore require FDA approval before being marketed. The FDA, however, has refrained from granting premarket approval while it determines what restrictions are necessary to assure safety and effectiveness of the kits.

The FDA has stated that it is in a dilemma in deciding the conditions under which the test kits can be used safely and effectively.²⁰ While some have argued that the kits should be given the widest possible distribution, consumer organizations, health professionals and specialists in AFP testing have expressed serious reservations. Specifically, these groups have informed the FDA that unrestricted use of the AFP kits could increase the number of abortions of normal infants, minimize identification of affected infants, and heighten anxiety over the outcome of pregnancy.²¹

Cognizant of these problems, the FDA has proposed regulations which focus upon controlled conditions for use. An AFP program would be required to have a coordinator who assures the FDA in writing that the program is in compliance with the FDA regulations. Within its organizational structure, a program would be required to provide access to services such as amniocentesis, ultrasonography and other laboratory services necessary for proper diagnostic follow-up.

¹⁶ Milunsky, *Prenatal Detection of Neural Tube Defects*, 244 J.A.M.A. 2731 (1980).

¹⁷ Golbus, Loughman, Epstein, Halsbasch, Stephens & Hall, *Prenatal Genetic Diagnosis in 3000 Amniocenteses*, 300 NEW ENG. J. MED. 157 (1979).

¹⁸ 45 Fed. Reg. 74,171 (1980).

¹⁹ 21 U.S.C. § 360c(f)(1).

²⁰ 45 Fed. Reg. 74,159 (1980).

²¹ *Id.*

Specifically, a competent diagnostic ultrasound service would be required to be available that is capable of detecting multiple fetuses, anencephaly, fetal death and gestational age. Amniocentesis would be available for all women in the program who requested it. The FDA has opined that its approval of the AFP test kit would significantly increase the number of amniocentesis procedures performed each year and has questioned whether the supply of such services would be adequate.²²

The program coordinator would be required to provide qualified personnel for counseling which would be based on a policy of voluntary participation, particularly with respect to available options when defects are detected. Laboratories would be required to be part of a program enrolled with the FDA to purchase AFP kits and could accept samples only from physicians who were similarly part of such a program.²³

Regardless of whether or not amniocentesis is performed in the context of an FDA enrolled program, there are recognized procedures designed to insure the medical and genetic integrity of the process. Typically, amniocentesis will be preceded by genetic counseling to insure that family pedigree can be recorded, relevant genetic facts can be evaluated and the psychological ramifications of pre-natal diagnosis may be explained.²⁴ It is recommended that amniocentesis also be preceded by an ultrasound investigation to determine the location of the placenta prior to uterine puncture and to evaluate the gestational age of the child.²⁵ The actual procedure is usually performed between the sixteenth and twentieth week of pregnancy by perforating the maternal abdominal wall and uterus. Amniotic fluid is then withdrawn.²⁶ In cases of multiple gestation it is possible to obtain amniotic fluid from both sacs.²⁷ The fluid is examined by karyotyping and biochemical analysis and this requires highly trained technicians and competent laboratories. Amniocentesis may also be performed transvaginally from the twelfth to the fifteenth week of pregnancy but this is considered risky.²⁸

²² 45 Fed. Reg. 74,161, 74,162 (1980).

²³ *Id.* at 74,162.

²⁴ Golbus, *supra* note 17, at 157.

²⁵ Milunsky, *supra* note 10, at 7.

²⁶ Fuchs, *Amniocentesis and Abortion: Methods and Risks*, in SYMPOSIUM ON INTRAUTERINE DIAGNOSIS (D. Bergsma, ed., 1971).

²⁷ Golbus, *supra* note 17, at 160.

²⁸ Fuchs, *supra* note 26, at 19.

Amniocentesis is by no means a risk-free procedure.²⁹ A study published in Britain in 1978 showed that damage to normal pregnancies from amniocentesis included increased change of respiratory distress syndrome, abruptio placenta and fetal morbidity.³⁰ Apart from the physical problems, emotional problems also have been reported.³¹

Finally, one of the biggest technical problems is the receiving and communicating of accurate test results.³² Current laboratory services are overburdened and it has been predicted that a major increase in demand may result in an unacceptable error rate. Also, because this is a potential \$100 million industry, there is the additional concern that profit may take precedence over quality control.³³

In a study conducted by the National Institute of Child Health and Human Development, there were six inaccurate diagnoses out of 1040 tests performed.³⁴ Two infants were born with Down's Syndrome which amniocentesis failed to detect. There were three cases of mistaken sexual identification and one mistaken diagnosis of galactosemia in a child who proved to be healthy at birth. A study published in 1979, indicated that out of 3000 tests performed, fourteen diagnostic errors were found, six of which affected the outcome of the pregnancy.³⁵ In that same study, of sixty-four abortions performed for chromosomal abnormalities, it was possible to verify only forty-two of them cytogenetically.

²⁹ The fetomaternal risks involved are: spontaneous abortion (In Golbus' study, *supra* note 17, published in 1979, which involved 3000 amniocenteses, there were 42 spontaneous abortions before 28 weeks. This represents a rate of 1.5% which is similar to the rate found in studies conducted in Europe and Canada.); secondary sterility, Fuchs, *supra* note 26, at 19; fetal death due to needle lesion: amniotic fluid infection, Fuchs, *supra* note 26, at 18, 19 (see also Alexander, *Workgroup Paper: Risks of Amniocentesis*, in PROCEEDINGS, *supra* note 15, at 20); placenta rupture, Friedman, *Legal Implications of Amniocentesis*, 123 U. PA. L. REV. 92, 106 n.87 (1974); inflammation of the amniotic sac, Gerbie, Nadler & Gerbie, *Amniocentesis in Genetic Counseling*, 109 AM. J. OBST. & GYN. 765, 767 (1971); fetal scarring and eye-damage, Friedman, *supra*, at 106 nn.89, 91; maternal peritonitis due to perforation of the intestines and fetomaternal hemorrhage due to perforation of the placenta, Fuchs, *supra* note 26, at 18, 19.

³⁰ *An Assessment of the Hazards of Amniocentesis: Report of the M.R.C. Working Party on Amniocentesis*, 1978 BRIT. J. OBST. & GYN. 85, Supp. 2.

³¹ Golbus, *supra* note 4; *Amniocentesis-Abortion Woes*, MED. WORLD NEWS, July 12, 1976, at 72; Brody, *Genetic Defects Sought in Fetus: Goal Is To Find Them When Abortion Is Still Possible*, N.Y. Times, May 12, 1976; Blumberg, Golbus & Hanson, *The Psychological Sequelae of Abortion Performed for a Genetic Indication*, 122 AM. J. OBST. & GYN. 799 (1975).

³² Golbus, *supra* note 17.

³³ Editorial, *supra* note 8.

³⁴ *Midtrimester Amniocentesis for Prenatal Diagnosis*, 236 J.A.M.A. 1471 (1976). See generally *Risks of Amniocentesis*, LANCET, Sept. 15, 1979, at 578; Milunsky, *Amniocentesis*, in GENETIC DISORDERS AND THE FETUS 27-42 (A. Milunsky, ed., 1979).

³⁵ Golbus, *supra* note 17.

II. ABORTION, EUTHANASIA AND AMNIOCENTESIS

Abortion, more often than not, is the preferred and recommended course of action where amniocentesis reveals abnormalities.³⁶ A National Institute of Health Consensus Development Conference estimated in 1979 that of fetuses found to be defective through pre-natal diagnosis, over 95% were aborted.³⁷ The time lapse between amniocentesis and abortion has been reported to vary between 32.2 days where a karyotype investigation was performed to 45.3 days when there was a biochemical investigation.³⁸

Abortion is generally chosen since few of the detected diseases can be cured or even treated *in utero* at the present time.³⁹ One physician has predicted that if intrauterine treatment of genetically diseased infants does become possible, most families will still choose abortion since it has already been reported that some parents have chosen to abort when the simple remedy of a corrective diet would have permitted a child to lead a normal life.⁴⁰ The state of the law in relation to abortion may also have some impact in this regard.

Elective abortion became a legal act in 1973.⁴¹ Although there are certain limitations on when it can be performed, it is always permissible when a woman's life or health is at stake.⁴² The Supreme Court never clearly defined the word "health" but implied that it should be employed in its broadest context.⁴³ The Court listed some of the detriments which affect health such as abandoning educational plans, sustaining a loss of income and foregoing the satisfaction of a career.⁴⁴ Although improbable, it is possible that these psychological and socio-economic considerations affecting health will not mature until the 280th day of gestation and thus, even at full term, under certain circumstances, a woman may choose abortion over regular delivery.⁴⁵

³⁶ Lieberman, *Psychological Aspects of Selective Abortion*, in SYMPOSIUM, *supra* note 26, at 20; Finley, Varner, Vinson & Finley, *Participants' Reaction to Amniocentesis and Prenatal Genetic Studies*, 238 J.A.M.A. 2377, 2379 (1977).

³⁷ DHEW, Public Health Service, NIH No. 79-2973, *ANTENATAL DIAGNOSIS: REPORT OF A CONSENSUS DEVELOPMENT CONFERENCE* 1-79.

³⁸ Golbus, *supra* note 17, at 160.

³⁹ Luy, *supra* note 10, at 36. However, successful prenatal treatment of genetic disorders of vitamin B12 metabolism has been reported. Jones, *Prenatal Diagnosis of Birth Defects*, 1 PERINATAL CARE 10, 17 (1977).

⁴⁰ McBride, *Prenatal Diagnosis: Problems and Outlook*, 222 J.A.M.A. 132, 135 (1972).

⁴¹ *Roe v. Wade*, 410 U.S. 113 (1973).

⁴² *Id.* at 164.

⁴³ *Id.* at 207, 208.

⁴⁴ *Id.* at 215.

⁴⁵ It becomes critical then to appreciate the definition of abortion, a term which has been variously

Prior to 1973, abortion was generally available for eugenic reasons under the nomenclature of a selective or therapeutic abortion.⁴⁶ The word eugenic was first used by Sir Francis Galton in 1883 as the name of a science directed toward improving hereditary qualities in a particular race by eliminating the unfit.⁴⁷ Eugenic abortions refer to those performed to prevent the birth of a defective or malformed child.⁴⁸

As the set of eugenic reasons constantly expands, we are confronted with a situation perhaps not imagined by the proponents of eugenic abortion prior to its legalization—sexual preference abortions. Chicago Tribune columnist Joan Beck makes this observation:

Abortion is increasingly being used to end the life of healthy unborn infants just because they are not of the sex their parents prefer. And almost all of the unborn babies aborted for no other reason except that they are of an unwanted sex are female.⁴⁹

The reasons underlying male sexual preference are unclear. One couple of Asian ancestry who had three daughters sought amniocentesis to ascertain whether the wife was carrying a boy since their culture placed a high value on male heirs. They stated that if the physician refused to perform the amniocentesis for that purpose, they would abort in any event.⁵⁰ Where physicians have been reluctant to perform amniocentesis for sexual preference reasons, some women have concocted various

defined. As will become evident, it is inappropriate to label the termination of pregnancy after viability an abortion. See, e.g., D. CAVERNAUGH & M. TALISMAN, *PREMATURITY AND THE OBSTETRICIAN* 4 (1969), where abortion is defined as "the expulsion or extraction of all (complete) or any part (incomplete) of the product of conception that weighs less than 500 g, alive or dead." See also J. GREENHILL, *OBSTETRICS* 265 (13th ed. 1965) ("interruption of pregnancy before the fetus is viable"); *A Statement on Abortion by One Hundred Professors of Obstetrics*, 112 *AM. J. OBST. & GYN.* 922 (1972) states:

It should be emphasized that abortion is medically defined as the termination of pregnancy before the end of the twentieth week. Regardless of the wording of a particular state law, therefore, abortions should not be performed for purely social reasons beyond this gestational age. Every effort should be made, of course, to perform abortions before the end of the first trimester.

Id. at 923.

⁴⁶ Nadler & Gerbie, *Role of Amniocentesis in the Intrauterine Detection of Genetic Disorders*, 282 *NEW ENG. J. MED.* 596, 599 (1970); Kindregan, *Abortion, the Law and Defective Children: A Legal Medical Study*, 3 *SUFFOLK U. LAW REV.* 226, 243-247 (1969).

⁴⁷ Kindregan, *supra* note 46, at 226.

⁴⁸ *Id.* at 246.

⁴⁹ Beck, *Abortion—Signs of Trouble Ahead*, *AMERICAN MEDICAL NEWS*, Nov. 22, 1976; see also Fletcher, *Ethics and Amniocentesis for Fetal Sex Identification*, 301 *NEW ENG. J. MED.* 550, 552 (1979).

⁵⁰ Young, *Now You Can Pick Your Child's Sex—If . . .*, *National Observer*, Oct. 30, 1976, at 3.

stories.⁵¹ In 1972 it was reported that a 38-year-old woman, desirous of a second son, sought amniocentesis under the guise of concern about Down's syndrome. After being informed that she was carrying a female, she obtained an abortion.⁵² This prompted an editorial in the Journal of the American Medical Association:

Abortion is often called "therapeutic." What name should be given to the abortion demanded solely because the sex of the fetus displeases the parents to be?⁵³

There seems to be no clear agreement among physicians on this issue. One physician has recommended that labs performing amniocentesis withhold the sex of the fetus unless it is crucial to the management of the case.⁵⁴ One of the initial developers and most ardent advocates of amniocentesis favors abortion where the test results show an undesired sex and would also favor abortion if the test revealed that the child would become afflicted with cancer in mid-life.⁵⁵ It has also been suggested that sexual preference abortions are no more objectionable than those performed to facilitate a woman's travel plans.⁵⁶ In any event, description of abortion based upon sexual preference as "eugenic" or "therapeutic" is largely academic in view of the legality of abortion under the current state of the law.⁵⁷

It is interesting to note that the rationale which supports eugenic abortion is equally supportive of eugenic euthanasia, when defective infants "slip through the screen and are born."⁵⁸ And, with viability now occurring in the second trimester and abortions following amniocentesis being performed in the second or third trimester, many defective infants will indeed be born.⁵⁹ Unlike abortion however, euthanasia is broadly held to be illegal. The act of birth confers legal personhood, a status which is protected by our judicial system. But present law is based upon the traditional western ethic which attaches value to all human life. Advocates

⁵¹ Knox, *Doctor's Dilemma: Abortion If Fetus is Wrong Sex*, Boston Globe, Aug. 11, 1976, at 1, col. 1 & 2.

⁵² *An Abuse of Prenatal Diagnosis*, 221 J.A.M.A. 408 (1972).

⁵³ *Abortion: A Special Demand*, 221 J.A.M.A. 400 (1972).

⁵⁴ *An Abuse*, *supra* note 52.

⁵⁵ HOWARD & RIFKIN, *supra* note 3, at 141.

⁵⁶ Fletcher, *supra* note 49, at 552.

⁵⁷ See text accompanying note 45, *supra*.

⁵⁸ Fletcher, *Abortion, Euthanasia and Care of Defective Newborns*, 292 NEW ENG. J. MED. 75 (1975).

⁵⁹ Henig, *The Child Savers*, N.Y. Times Mag., March 22, 1981, at 34.

of a quality of life ethic do not necessarily recognize a continued right to life after birth. Nobel laureate, Sir Francis Crick, has stated that "... no newborn infant should be declared human until it has passed certain tests regarding its genetic endowment and ... if it fails these tests, it forfeits the right to life."⁶⁰ An equally preposterous suggestion is that a child achieve a minimum I.Q. test score of 20-40 before being considered human.⁶¹

III. AMNIOCENTESIS AND WRONGFUL LIFE/BIRTH LITIGATION

The existence of amniocentesis as a pre-natal detection technique has generated a unique set of malpractice litigation, specifically labeled wrongful life actions.⁶² These actions are brought by parents on behalf of a child seeking damages resulting from the fact of the child's birth. The theoretical justification for the action is that but for the defendant/physician's negligence, the child would not have been born.⁶³

Wrongful life actions are distinguishable from wrongful birth actions which are brought by the parents of the affected child and typically allege that had they been informed of the existence of amniocentesis, it would have been performed and the defective child would have been aborted. In wrongful birth actions the parents usually seek damages for pain and suffering, loss of consortium, emotional distress, loss of wages, medical expenses and the costs of raising the child.⁶⁴ In 1967, damages were first awarded to parents in a wrongful birth case and the trend today is toward recovery for the parents.⁶⁵

Courts have uniformly rejected wrongful life claims on two grounds.

⁶⁰ Frankel, *The Specter of Eugenics*, Commentary, March, 1974.

⁶¹ WEBER, WHO SHALL LIVE? 77 (1976).

⁶² See generally *Father and Mother Know Best: Defining the Liability of Physicians for Inadequate Genetic Counseling*, 87 YALE L.J. 1488 (1978); Capron, *Tort Liability in Genetic Counseling*, 79 COLUM. L. REV. 618 (1979); Trotzig, *The Defective Child and the Actions for Wrongful Life and Wrongful Birth*, 14 FAM. L.Q. 15 (1980).

⁶³ The "amniocentesis" cases are: Fiegelson v. Ryan, N.Y.L.J. Feb. 24, 1981, at 5; Berman v. Allen, 80 N.J. 421, 404 A.2d 8 (1979); Becker v. Schwartz, 60 App. Div. 2d 587, 400 N.Y.S.2d 119 (1977), modified, 46 N.Y.2d 401, 413 N.Y.S.2d 895 (1978); Gildiner v. Thomas Jefferson Univ. Hosp., 451 F. Supp. 692 (E.D. Pa. 1978); Johnson v. Yeshiva Univ., 53 App. Div. 2d 523, 384 N.Y.S.2d 455 (1976), aff'd, 42 N.Y.2d 818, 396 N.Y.S.2d 647 (1977); Karlsons v. Guerinot, 57 App. Div. 2d 73, 394 N.Y.S.2d 933 (1977); Greenberg v. Klot, 47 App. Div. 2d 765, 367 N.Y.S.2d 966, leave to appeal denied, 37 N.Y.2d 707, 375 N.Y.S.2d 1026 (1975).

⁶⁴ Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (1980). For an excellent collection of the recent wrongful birth cases, see Trotzig, *supra* note 62, n.6.

⁶⁵ Custodio v. Bauer, 251 Cal. App. 2d 303, 59 Cal. Rptr. 463 (1967).

First, it is difficult to assess damages. Tort damages are compensatory in nature and designed to put the party in the position in which he or she would have been but for the negligence of the defendant. In a wrongful life action the court would be required to weigh the value of an impaired life against the non-existence of that life.⁶⁶

The second justification for judicial rejection of wrongful life claims is based on a public policy which favors the continuing reaffirmation of the value of life ethic. The most recent case involving a wrongful life claim noted that "... in some fashion, a deeply held belief in the sanctity of life has compelled some courts to deny recovery"⁶⁷

The landmark wrongful life case which has served as precedent in denying relief in the amniocentesis cases is *Gleitman v. Cosgrove*.⁶⁸ Mrs. Gleitman contracted rubella during the first trimester of her pregnancy and her child was born with serious impairments. The plaintiffs alleged that the defendant knew of Mrs. Gleitman's condition but failed to inform her of any potentially harmful consequences to the child and therefore sought damages for wrongful life and wrongful birth. The New Jersey Supreme Court denied recovery to either the child or the parents stating that "life with defects" was better than "no life at all" and that it would be impossible to assess damages. Even if Mrs. Gleitman could have obtained a legal abortion, the court noted that public policy disfavored allowing recovery for "the denial of the opportunity to take an embryonic life."⁶⁹

Gleitman has been followed in virtually all wrongful life cases, including the amniocentesis cases, to deny damages to the child. However, since the legalization of abortion in 1973, there has been a retreat from that holding with respect to the parents' right to recover. In *Berman v. Allen*,⁷⁰ the Supreme Court of New Jersey recognized a cause of action by parents against a physician for medical malpractice in failing

⁶⁶ See, e.g., *Berman v. Allen*, 80 N.J. 421, 425, 404 A.2d 8, 12 (1979). See also Comment, *Wrongful Life and a Fundamental Right to be Born Healthy: Park v. Chessin, Becker v. Schwartz*, 27 BUFFALO L. REV. 537 (1978); Kashi, *The Case of the Unwanted Blessing: Wrongful Life*, 31 U. MIAMI L. REV. 1409 (1977).

⁶⁷ *Curlender v. Bio-Science Laboratories* 165 Cal. Rptr. 477, 486 (1980).

⁶⁸ 49 N.J. 22, 227 A.2d 689 (1967). The first wrongful life claim arose in *Zepeda v. Zepeda*, 41 Ill. App. 2d 240, 190 N.E.2d 849 (1963), cert. denied, 379 U.S. 945 (1964). A healthy child conceived out of wedlock sued his father, claiming injury due to his illegitimate birth status. While the court recognized that a tortious act had been committed, it denied recovery on public policy grounds stating that such a decision should be made by the legislature. See also *Williams v. State*, 18 N.Y.2d 481, 276 N.Y.S.2d 885, (1966).

⁶⁹ 49 N.J. at 30, 227 A.2d at 693.

⁷⁰ 80 N.J. 421, 404 A.2d 8 (1979).

to advise of the existence of amniocentesis after plaintiffs' child was born with Down's Syndrome. The parents asserted that had they been advised of amniocentesis, it would have been performed and the defective child would have been aborted.

The infant's claim for wrongful life was rejected, however, based on a reaffirmation of the value of life ethic articulated in *Gleitman*. The court went to great lengths to reaffirm "the sanctity of life," quoting from the Declaration of Independence and the United States Constitution that "life is one of three fundamental rights of which no man can be deprived without due process."

The retreat from *Gleitman* was inextricably linked with the Supreme Court's decision in *Roe v. Wade* which legalized abortion. The *Berman* court stated that "public policy now supports, rather than militates against, the proposition that [a woman] not be impermissibly denied a meaningful opportunity to make [the] decision to abort at least during the first trimester of pregnancy."⁷¹ Thus, the essence of the injury in *Berman* was that the parents were deprived of the right to exercise a decision whether or not to abort.

While *Berman* continued the *Gleitman* rule disallowing economic damages, it recognized that the defendant physicians had breached a duty to the parents by failing to inform them of the availability of amniocentesis. This deprived the parents of the exercise of an option with respect to acceptance or rejection of parenthood. Thus, the parents were allowed to recover the "monetary equivalent of their distress" without making any allowances for "the love and joy they will experience as parents."⁷²

Damages for pecuniary loss were allowed in *Becker v. Schwartz*,⁷³ a wrongful life and wrongful birth action involving the failure of the physicians to inform the parents of the existence of amniocentesis resulting in the subsequent birth of a mongoloid child. The court held that the parents could recover for their pecuniary loss but not for emotional distress. In denying the child's claim the court reaffirmed the value of life ethic and questioned whether wrongful life claims should ever be recognized given the impossibility of knowing the true desires of the child.⁷⁴

⁷¹ 80 N.J. at 431-32, 404 A.2d at 13-15.

⁷² *Id.*

⁷³ 60 App. Div. 2d 587, 400 N.Y.S.2d 119 (1977), modified, 46 N.Y.2d 401, 413 N.Y.S.2d 895 (1978).

⁷⁴ This child was subsequently put up for adoption. *Baby in Malpractice Suit Was Put Up for Adoption*, N.Y. Times, Feb. 17, 1979, at 23, col. 1, at 24, col. 1.

In *Johnson v. Yeshiva University*,⁷⁵ also a wrongful life and wrongful birth action, no liability was imposed upon a physician for failure to perform amniocentesis despite subsequent birth of a defective child. The court upheld the physician's conduct as a "permissible exercise of medical judgment and not a departure from then accepted medical practice." In this case the plaintiff failed to establish that on the basis of her medical history and the state of medical knowledge about amniocentesis in 1969, the defendant physician departed from accepted medical practice.

In *Gildiner v. Thomas Jefferson University Hospital*,⁷⁶ the court recognized the existence of a cause of action for the negligent performance and interpretation of amniocentesis. After Linda Gildiner discovered that she was pregnant, plaintiffs underwent a Tay-Sachs test which determined that they were both carriers of Tay-Sachs disease. Amniocentesis was performed and plaintiffs were informed that the results eliminated any possibility that their child would be afflicted with Tay-Sachs. Upon the birth of their child afflicted with Tay-Sachs, the parents instituted a wrongful life and birth action.

Based upon the *Gleitman* rationale, the court rejected the child's wrongful life action. But, the court recognized a cause of action on behalf of the parents based upon general negligence principles. It noted that a failure in the performance or interpretation of amniocentesis could result in a healthy fetus being aborted or in the unwanted birth of a child with Tay-Sachs disease and that both of these occurrences violated the public policy of the state. *Gildiner* is internally inconsistent. By accepting *Gleitman* the court accepts the proposition that life is more precious than non-life. Therefore, the birth of a child whether unwanted by parents or afflicted with Tay-Sachs disease cannot be violative of a state's public policy.

The most recent case involving amniocentesis was dismissed on procedural grounds. In *Feigelson v. Ryan*,⁷⁷ damages were sought against

⁷⁵ 53 App. Div. 2d 523, 384 N.Y.S.2d 455 (1976), *aff'd*, 42 N.Y.2d 818, 364 N.E.2d 1340, 396 N.Y.S.2d 647 (1977). *But see* *Karlsons v. Guerinot*, 57 App. Div. 2d 73, 394 N.Y.S.2d 933 (1977), wherein the plaintiff, a 37-year-old woman brought an action after the birth of her mongoloid child. She alleged that had she been informed of the existence of amniocentesis, she would have undergone the process and aborted the defective child. Recovery was allowed the mother on the theory that the defendants had a duty to provide proper prenatal care. The breach of duty consisted of a failure to test for the existence of the deformity in light of the mother's previous history which included a thyroid condition and the birth previously of a deformed child.

⁷⁶ 451 F. Supp. 692 (E.D. Pa. 1978).

⁷⁷ N.Y.L.J. Feb. 24, 1981, at 5.

physicians for their failure to perform amniocentesis. An artificial insemination was performed upon plaintiff which resulted in pregnancy. After the child was born on February 19, 1976, he underwent chromosomal analysis and it was discovered that he suffered from a chromosomal disorder causing mental retardation and physical disability. Plaintiffs were informed of this problem in May, 1977, and brought an action contending that they were improperly advised regarding the risks of pregnancy for women over the age of thirty-five. Had they been properly informed, it was alleged, the mother would have undergone amniocentesis and upon discovery of the genetic defect, would have aborted the child. However, New York's three year statute of limitations in malpractice cases had lapsed and the case was dismissed.

One of the issues raised by the amniocentesis cases is that of how a court would react if faced with an action by parents who were unhappy about the sex of their child. Considering the growing use of amniocentesis to determine fetal sex and the *Berman* court's rationale in support of a parental right of action for being deprived of the ability to make an abortion decision, this potentiality is not so remote. It may well be that these cases would be decided in the same manner as the cases dealing with unwanted but otherwise healthy children. It is generally held that plaintiffs who have attempted to prevent the birth of a child may collect for medical expenses, loss of income, and pain and suffering from the defendant whose negligence caused the child's conception.⁷⁸

IV. THE DILEMMA

The increased availability, advocacy and use of amniocentesis as a panacea against the birth of infants possessed of defects or as a guarantee of beautiful children or children of a desired sex, presents serious legal-ethical-moral considerations. While the potential for a perfect human being seems to become real, the trade-off is diminished protection for human beings *qua* human beings. Between these competing values lies a host of uncomfortable issues.

There is what the British medical journal LANCET refers to as "the ethical problems of over-kill of healthy fetuses."⁷⁹

⁷⁸ See Comment, *Liability for Failure of Birth Control Methods*, 76 COLUM. L. REV. 1187 (1976).

⁷⁹ *The Risk of Amniocentesis*. LANCET, Dec. 16, 1978, at 1287.

The dilemma lies in deciding what value should be placed on the gains of terminating affected fetuses and the losses of killing normal fetuses. These cannot simply be weighed against each other in numerical terms. The value of terminating affected fetuses must depend on the likely degree of handicap and its effect on parents, their families and society; some fetuses will be so severely affected that they will be stillborn or die soon after birth, in which case amniocentesis and termination cannot be said to have averted handicap. At the other end of the scale, some will be only mildly affected and have a prospect of almost normal lives. Between these two extremes lies a full range of physical and mental disabilities.⁸⁰

Are we ready to accept the consequences of over-kill?

Additionally, when the possibility of error is considered, the potential for litigation is endless. In the National Institute of Child Health and Human Development test which was sponsored by the government, and which, one assumes, would have been conducted under ideal conditions, there were errors. Who should bear the risk of loss in these cases? The physician, genetic counselor, laboratory, parents? How should damages be assessed when the aborted child is found to be without defect or of the desired sex?

Finally, the question remains as to whether a law which permits parents to eliminate a child of undesired sex before birth would extend after birth where diagnosis was inaccurate? The majority of the population would probably frown upon the exercise of the latter course of action as homicide. Psychologically, *in utero* death by abortion is preferred to *ex utero* death, since, as noted by the California Medical Journal in 1970, a quality of life mentality has succeeded in separating the idea of abortion from the idea of killing.⁸¹ This observation is reinforced by a comment from the mother of a child with Tay-Sachs disease who has stated that knowing that a child affected with Tay-Sachs can be "detected and aborted" meant that she could become pregnant again without fear of "watching" another of her children die.⁸²

The rights associated with parenthood seem somewhat confused among the rights associated with marriage and childrearing. There is a right to conceive⁸³ and not to conceive;⁸⁴ a right to know what has been

⁸⁰ *Id.* at 1288.

⁸¹ *A New Ethic for Medicine and Society*, 113 CAL. MED., 67, 68 (1970).

⁸² *Antenatal Diagnosis*, *supra* note 14, at 1669.

⁸³ *Skinner v. Williamson*, 316 U.S. 438 (1942) (right to procreate).

⁸⁴ *Eisenstadt v. Baird*, 408 U.S. 438 (1972) (right of unmarried persons to use contraceptives); *Griswold v. Connecticut*, 381 U.S. 479 (1965) (right of married persons to use contraceptives).

conceived⁸⁵ and to eliminate the same.⁸⁶ The logical outcome of this quality of life ethic is that these rights may become obligations, social or otherwise. Ethicist John Fletcher has stated:

With the availability of the technology and know-how permitting prevention of many genetically based congenital abnormalities, there may be developing as a corollary a social attitude which demands such use. In general, if a congenital abnormality can be avoided, then it should be, and those individuals who do not partake of these advances will be socially ostracized.⁸⁷

When will parents be forced to forfeit offspring who fail the quality control specifications of judges? The idea is not entirely unreasonable in a country where, under compulsory sterilization statutes, thousands of Americans were sterilized involuntarily in a campaign to eliminate biological inferiors from the American populace.⁸⁸

While one of the leading experts in amniocentesis, Dr. Henry L. Nadler, believes that performing amniocentesis in every pregnancy "would be like a hunting expedition,"⁸⁹ it could become compulsory in the name of public welfare as did sterilization.⁹⁰ These observations become less speculative as the quality of life ethic fully displaces the traditional ethic and the obligation to beget only quality "products of conception" is enforced. Already, it has been suggested that there be compulsory controls when there is a failure to adhere to "humane minimal standards of reproduction."⁹¹

Coercion may be subtle and as one physician has noted, "... it is sometimes difficult to distinguish coercion from choice."⁹² If amniocentesis becomes publicly funded and large-scale advertising is undertaken, there is the problem of guilt for women who decline to have the test performed.⁹³ It is possible that amniocentesis could become publicly

⁸⁵ *Becker v. Schwartz*, 60 App.Div. 2d 587, 400 N.Y.S.2d 119 (1977), *modified*, 46 N.Y.2d 401, 413 N.Y.S.2d 895 (1978); *Park v. Chessin*, 400 N.Y.S.2d 110 (1977) (physician may be held liable in negligence for failing to inform patients of the availability of amniocentesis in certain circumstances and of the risk of bearing abnormal children).

⁸⁶ *Roe v. Wade*, 410 U.S. 113 (1973).

⁸⁷ Sorenson, *Some Social and Psychologic Issues in Genetic Screening*, quoting John Fletcher, in SYMPOSIUM, *supra* note 26, at 177.

⁸⁸ HOWARD & RIFKIN, *supra* note 3, at 57. See also Vacari, *Legal Aspects of Compulsory Sterilization in America*, 3 INT'L REV. NAT. FAM. PLAN. 1 (1979).

⁸⁹ McBride, *supra* note 40, at 132.

⁹⁰ See Friedman, *supra* note 29, at 122-142.

⁹¹ *Laws Forbidding Some Persons From Reproducing Held Justified*, OBS. & GYN. NEWS, Aug. 1, 1979.

⁹² Editorial, *supra* note 8.

⁹³ *Id.*

funded to the extent that abortion is so funded and to the extent that AFP screening programs become mandatory. The latter possibility is extremely remote, however, since most commentators oppose any form of mandatory screening programs.⁹⁴

CONCLUSION

Given the choice, few if any women would choose to conceive a defective child just as few would choose to marry a person with a progressively debilitating disease. But, after conception occurs, removing defects from the womb should not be approached with the mechanical nonchalance of removing a defective refrigerator. As noted by the New York Court of Appeals, that which exists in the womb is human and it is unquestionably alive.⁹⁵

Medicine must encourage research to treat and cure *in* and *ex utero* or there are no real choices. "Abortion is never therapeutic for the fetus . . ." ⁹⁶ Law must safeguard zealously the rights of those deemed "defective," the most vulnerable members of society. In short, members of the legal-medical community must insure that emphasis be placed upon eliminating the "defect" not the "defective." Otherwise, the apotheosis of human quality control will lead us out of control.

⁹⁴ See, e.g., *supra* note 15, at 37, 69.

⁹⁵ *Byrn v. N.Y.C. Health & Hosp. Corp.*, 31 N.Y.2d 194, 199, 335 N.Y.S. 2d 390, 392 (1972), appeal dismissed, 410 U.S. 949 (1973). In *Byrn*, the New York Court of Appeals upheld a law permitting abortion but stated:

It is not effectively contradicted, if it is contradicted at all, that modern biological disciplines accept that upon conception a fetus has an independent genetic "package" with potential to become a full-fledged human being and that it has autonomy of development and character although it is for the period of gestation dependent upon the mother . . . and it is unquestionably alive.

⁹⁶ Powledge & Fletcher, *Guidelines for the Ethical, Social and Legal Issues in Prenatal Diagnosis*, 300 NEW ENG. J. MED. 168, 171 (1979).

