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Prenatal Diagnosis: A Reappraisal

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Moral judgment involves a delicate interplay of ideals and facts. A reflective moral appraisal of an activity must be based not only on clear-eyed commitment to ideals, but also on patient analysis of the factual dimensions of the activity at hand. If this is so, moral judgment must be both as fixed as our commitment to traditional moral principles and as mobile as our evolving human experience. Moral appraisal of medical technology is a case in point: commitment to respect all human life must be constantly integrated with knowledge of the facts of expanding medical power.

Those who are morally opposed to abortion, even so-called therapeutic abortion, have had good reasons to be wary of prenatal diagnosis.¹ The foremost of these reasons, of course, is the close factual association of techniques like amniocentesis with selective abortion. In the face of these facts, commitment to respect all human life has appeared to be incompatible with the search for defects in the fetus. Recently, however, there have been medical developments

which hold out the possibility of factually separating prenatal diagnosis from selective abortion.²

If prenatal diagnosis can now occur in an environment free from association with abortion and if it can bring important benefits of its own, then it is time for a reappraisal of the moral status of prenatal diagnosis. This is what I propose here. First, the arguments against the practice of prenatal diagnosis will be reviewed. Secondly, these new medical developments, as well as other reasons favoring prenatal diagnosis, will be presented. Finally, a concluding reappraisal will be offered.

I. Reasons to Oppose Prenatal Diagnosis

As already stated, the major moral concern about prenatal diagnosis is its close empirical association with selective abortion of fetuses found to have some defect. The connection between the two was perceived to be so close, in fact, that in many centers where amniocentesis was performed in its early years (over a decade ago) commitment to abortion of a defective fetus was made a prerequisite for obtaining the procedure. Apparently this was or still is the case in some centers into the 1980s.³ The justification offered for establishing this prerequisite is the existence of some risk to the (normal) fetus and the desire to restrict access to a limited resource.

Even when no such explicit prerequisite prevails, the linkage between prenatal diagnosis and selective abortion has been close. Although the results of the vast majority of these procedures are negative, i.e., they reveal no fetal defect,⁴ in the minds of many is a readiness to abort should a defect be identified. In a recent Canadian study, for example, of 74 women who were about to undergo amniocentesis, 84% reported an intention to abort if a genetic defect was diagnosed; 47% even reported that reaching a decision on abortion in this situation was not difficult.⁵

Undoubtedly, among the reasons why so many of these women found this choice an easy one is the presumption that of all abortion decisions, the choice of selective abortion based on genetic defect is the most justifiable. This presumption has some appeal when one conceives of the range of frivolous considerations which may produce abortions in a situation of widely available abortion "on demand." By contrast, one can readily understand and appreciate the tragic dimensions of a bad prenatal diagnosis. Diagnosis of serious defect in the fetus causes the woman to be concerned about the effects on her personal life, the life of her family, the affected child, society as a whole, and on family finances.⁶ Admitting this, there remains a sense in which this sort of abortion choice is *more* morally objectionable than others. Presumably, the dominant reason for abortion decisions in general is the desire not to have a child — any child. In this case,

however, the desire is not to have *this* child, or this *kind* of child. Implied in this choice, then, is a denial of the fundamental equality of all persons and the establishment, instead, of kinds of human persons, some of whom are acceptable, some of whom are not.⁷ Prenatal diagnosis thus appears as an attempt to identify, so as to destroy, the wrong kind of human person.

Another concern about prenatal diagnosis is that its availability and its association with selective abortion may be encouraging some women to delay childbearing choices until decades of their lives are known to be associated with higher incidences of genetic anomalies.⁸ Of course, there are other, more benign reasons why women are delaying pregnancies — educational goals, career aspirations, the struggle to attain their rightful (but long denied) place in society generally.⁹ Still, one cannot help but suspect that the availability of prenatal diagnosis, coupled with selective abortion, is making the higher risks of advanced age pregnancies more acceptable to some.

Of concern as well is the use of prenatal diagnosis, not for identification of fetal defect, but for identification of an undesirable gender. Followed by selective abortion, prenatal diagnosis can be a vehicle for sex selection. Though the use of prenatal diagnosis for this purpose was strongly opposed in guidelines offered by the Genetics Research Group of the Hastings Center,¹⁰ the co-director of the group, John C. Fletcher, subsequently changed his view. His revised opinion turns on the claim that to accept the logic of *Roe v. Wade* (he does) is to accept abortion for *any* reason, even the most trivial. He argues that “. . . it is inconsistent to support an abortion law that protects the absolute right of women to decide and, at the same time, to block access to information about the fetus because one thinks that an abortion may be foolishly sought on the basis of the information.”¹¹ At least one commentator has found some irony in Fletcher’s consistency. Citing studies that show that non-Hispanic American wives prefer sons to daughters generally, and overwhelmingly prefer that sons be first-born, sociologist Gertrud Lenzer thinks it unlikely that the high court meant, “. . . to guarantee women the right of self-determination for the purpose of discriminating against their own kind by either doing away with the fetuses of their own sex or by choosing male children as their first-borns . . .”¹² Irony aside, sex selection by way of prenatal diagnosis and abortion is clearly repugnant to the ideal of respect for the dignity of all human lives.

Finally, there are moral issues raised by prenatal diagnosis even without reference to abortion. Though sonography carries no known risk, amniocentesis, amniography, and fetoscopy all carry small but real risks of fetal injury.¹³ The imposition of a risk on a human being always requires moral justification. Furthermore, since the fetus is obviously incapable of giving or withholding informed consent for the

procedure, proxy consent from the mother must suffice. This fact raises the possibility of cases of conflict of interest between mother and fetus, and the resultant question of the validity of the former’s informed consent.¹⁴

II. Reasons for Favoring Prenatal Diagnosis Now

The major reason why someone committed to respect for all human life must now reappraise opposition to prenatal diagnosis is the fact that some, and a growing number, of fetal defects can now be treated in utero. In a 1981 article, Drs. Michael Harrison, Mitchell Golbus, and Roy Filly listed the following conditions amenable to treatment in utero: deficient pulmonary surfactant (pulmonary immaturity), anemia-erythroblastos and hydrops, hypothyroidism and goiter, methylmalonic acidemia (B12-dependent), multiple carboxylase deficiency (biotin-dependent), nutritional deficiency and intrauterine growth retardation, bilateral hydronephrosis (urethral obstruction), diaphragmatic hernia, and obstructive hydrocephalus. The doctors assert that “[t]he rationale for early correction is unique to each anomaly, but the principle remains the same: continued gestation would have a progressive ill effect on the fetus.”¹⁵ In utero intervention to correct these anomalies, on the other hand, offers the possibility of lessening their negative impact on the developing fetus and of enhancing his or her chances of living a normal and satisfying human life. Two of the more dramatic cases can represent the possibilities here.

Prenatal diagnosis of a 41-year-old woman revealed the presence of twins, one of whom had a markedly distended bladder.¹⁶ After several unsuccessful attempts to treat this swelling (and the urinary obstruction causing it) in less invasive ways, a tiny catheter inside a needle was passed through the mother’s abdomen and placed in the fetus, one end in its bladder, the other in the amniotic sac. The bladder immediately emptied. At birth there were other anomalies which required surgery. But “[t]he postoperative course was unremarkable with the neonate demonstrating normal pulmonary and renal function.”¹⁷ The in utero catheterization probably saved the child’s life, since infants born with high-grade obstructions such as these often die. “[C]ontinued obstruction will result in a kidney, the development of which is so impaired as to prevent survival, while relief of the obstruction may allow sufficient development as to support postnatal life and allow ‘catch-up’ development during early childhood.”¹⁸

In a second remarkable case, prenatal sonography of a 26-year-old woman revealed a fetus suffering from hydrocephalus.¹⁹ The great danger of this buildup of fluid pressure on the brain is severe brain damage. Even when this fluid pressure is relieved by a shunting procedure at birth, much irreparable damage can already have occurred. Furthermore, the increased size of the fetus’s head usually causes gross

disfigurement and distortion of facial features, as well as greater difficulty for fetus and mother if a vaginal delivery is attempted. Face 1 with these prospects, an in utero shunt was specially designed and 1 placed, by needle through the mother's abdomen, into the head of the 24-week-old fetus. The shunt operated as planned, relieving the fluid pressure on the fetus's brain, until the 32nd week. At that time the shunt became obstructed and a Caesarean delivery was performed. "At delivery the infant was vigorous and active." There was no question that the shunt had prevented the usual facial disfigurement; the child's face and skull appeared normal. Though only time and development will confirm normal brain function, the child's brain is . . . clearly more normal than it would have been if no treatment had been given.²¹

These dramatic cases, and the several others being reported with more and more frequency, demonstrate that we are on the verge of having a powerful new medical technology which will allow in utero treatment of a growing list of fetal defects. Obviously, such treatment is impossible without prenatal diagnosis. Hence the first reason for favoring prenatal diagnosis is the new treatment potential it opens and the obvious reduction in human deaths and sufferings such treatment can mean. Clearly there are ethical problems of proportionate risk and informed consent raised by these in utero procedures (consider the implications of the presence of the normal twin in the first case, for example). Nevertheless, ". . . one clearly positive aspect is that prenatal diagnosis of a fetal malformation may now lead to treatment rather than abortion."²²

The character of future advances in in utero treatment may be surmised by reference to recent research on primates.²³ One of the most common major congenital malformations, neural tube defect (especially spina bifida), is being attacked with research on the fetuses of rhesus monkeys. In the U.S., approximately two of every thousand births are afflicted with a serious neural tube defect (in the U.K., it is six to eight per thousand), and this anomaly is often associated with hydrocephalus, mental retardation, disfigurement and paralysis of limbs, urinary and bowel incontinence, early demise, and, of course, the acute human sufferings consequent to these conditions.²⁴ Those researching with these primates have developed a bone paste which, when inserted into the affected monkey fetus, can facilitate the closing of fissures of the neural tube. Such work also has revealed some surprising advantages to fetal surgery. As one might expect, earlier treatment has the advantage of limiting the range of other problems which are caused by the neural tube defect itself. But one might not have expected that: 1) the risk of immune rejection of bone transplant is lowered dramatically because of the undeveloped character of the fetal immune surveillance system, 2) there is far more rapid healing in the fetus than in the neonate, 3) infections are combatted by transplacental passage of maternal immune factors, 4) the womb

environment makes the post-operative period technically simplified in general, and 5) medicines administered directly to the fetus are more effective at reduced doses than those routed through the mother.²⁵ One other startling result has been reported: in early stages of development, fetal monkeys have the ability to regenerate severed limb buds. This finding opens the exotic possibility that early diagnosis of (non-genetic) limb defects in human fetuses might some day be treatable by regenerative surgery in utero.²⁶

Not only do these present and foreseeable prenatal treatments promise a reduction of sufferings for affected children and their families and an enhancement in the quality of life for both, but they also augur another important development. Prenatal diagnosis and treatment of affected fetuses are ushering in a new conceptualization of the fetus itself: the fetus as patient. Practitioners in the field of fetal treatment are concerned about how to adapt the traditional doctor-patient relationship to this new patient and have even issued calls for third party fetal advocates to handle informed consent issues.²⁷ The significance of this development to those who are committed to respect for fetal life can be measured by the degree of distress it has caused to those not sharing this commitment. John Fletcher, who believes that a woman's moral right to abort for even the most frivolous of reasons is absolute, feels an apparent inconsistency in at once encouraging fetal therapy and respecting parental choice about abortion. "Is it not contradictory," he asks, "for physicians to speak of the fetus as 'patient,' when one of the stipulations for that role is that physicians would not under any circumstances abandon such an individual?"²⁸ And William Ruddick and William Wilcox, who side-step the fetus-as-patient issue by labeling fetal therapy a gynecological procedure, ask the following tough questions: "Does the fetus have a new moral status by virtue of the new therapeutic options available to it? If so, will physicians who currently perform abortions find themselves in a moral bind?"²⁹ There certainly must be something right about prenatal diagnosis if it can be part of the provocation for this sort of reflection.

That something right probably has to do with moral psychology. Though our moral values and obligations regarding the fetus rest properly on the nature of the being at issue, the psychological capacity to feel those values and duties concretely, and thus to make them efficacious in our lives, depends for many of us on the ability to interact with and share the world of this being. In what appears now as a remarkably prescient article, Roger Wertheimer in "Understanding the Abortion Argument" (1971) asked, almost rhetorically, whether our conception of the fetus wouldn't change if pregnancy caused the maternal abdomen to become transparent so that the fetus could be seen; or if the fetus could be removed from the womb for short periods of time, fondled, and returned — and this handling made for

healthier babies. Imagining this, he asked, "What would you think of aborting the fetus?"³⁰ But this is nearly a description of what prenatal diagnosis now allows. Real-time sonography virtually allows us to see the fetus. Though fetal surgery does not remove the fetus for fondling, it does let us touch the fetus, and in doing so, make it healthier. Prenatal diagnosis and the fetal treatment made possible by it, allows us to interact with the fetus, to bring the fetus into our world in a graphic manner. No doubt this will have a growing impact on our collective psychology. It will make it harder and harder to ignore the moral standing of fetuses who are aborted, even as we put greater and greater energies and expense into caring for and curing other fetuses in utero.

There are two other reasons for favoring prenatal diagnosis now. Since the vast majority of diagnoses are negative, it is likely that such results will not only relieve considerable parental anxiety, but will also save some fetuses who would otherwise be aborted because of concerns based on maternal age or the previous birth of a child with a genetic defect. While it is true that this sort of benefit is only possible given the background of the ongoing moral costs of abortion, present social reality cannot be ignored. Furthermore, in a situation of widely available abortion on demand, it is reasonable to assume that a woman or couple seeking prenatal diagnosis are doing so because they very much want a child. Good news about the fetus in this context has a strong likelihood of leading to a live birth.

Secondly, even when the news is not good, there are considerations which favor prenatal diagnosis. Depending on the nature of the fetal defect, the timing and method of delivery may be changed to enhance its potential (i.e., an early Caesarean delivery), and steps can be taken to ensure all the proper medical expertise and that equipment is in place and ready for any needed correction and support at birth.³¹ Furthermore, there is another kind of preparation which may augment the affected fetus's future potential: psychological preparation of the mother or couple. We know that the birth of a defective newborn can be traumatic for the parents and that it is associated with psychological grieving processes.³² If parents-to-be of a defective child can have several months to work through this shock and grief, their early relationship with and care of their child can be enhanced. Knowledge of the impending arrival of such a child can also be the occasion for increasing the social support available to mother or couple, and such social support is highly correlated with increased maternal attachment to the fetus, just as stress is highly correlated with decreased maternal attachment.³³ Given these opportunities to improve on a bad human situation — opportunities lost without prenatal diagnosis — it may well be that parents have a moral right to prenatal diagnosis, a right to be enabled to do the best they can to lessen the sufferings and enhance the quality of life for their future child and for themselves.

III. Concluding Reflections

Having reviewed the new facts which make a reappraisal of prenatal diagnosis necessary, it is time now to draw some conclusions. The major argument against prenatal diagnosis was its close empirical association with selective abortion. New developments in fetal treatment in utero show that abortion no longer need be the only medical response open to those diagnosing the existence of a defective fetus. But an obvious question remains. Though these new options exist, will selective abortion still be the likeliest result of prenatal diagnosis of a fetal defect? More pointedly, will those persons and institutions who oppose abortion become its unwitting accomplices by providing prenatal diagnoses in good faith — only to find their patients who receive bad news leaving for other reasons and institutions to secure abortions? And if this did become the case, to what extent would those providing prenatal diagnoses bear responsibility for this result? These are hard questions.

The most candid response to the first concern must be that some, perhaps many, who receive news of a fetal defect, will have no real treatment option available; or if they do, will elect not to accept the risks of fetal treatment and the remaining likelihood of some lessened, but perhaps significant, defects in their future child. Given the present cultural environment, these persons will opt for abortion. Moreover, sex selection will likely remain legal, and therefore it cannot be ruled out as a possible consequence of prenatal diagnosis. It follows, then, that if persons and institutions who oppose abortion (I am thinking especially of Catholic hospitals) provide prenatal diagnosis, some will use the information gathered to decide for abortion. Admitting this, should prenatal diagnosis be done by those who oppose abortion?

A first point to be made here is that persons may not be morally required to cooperate with an activity they regard as wrong and offensive to their conscience. Consequently, if a hospital opposing abortion becomes aware that its (non-emergency) services are being used to abet abortion, it may rightfully refuse to provide these services to that individual or couple. Physicians and hospitals may even inquire at the outset of any professional relationship as to whether abortion is conceived to be an option by their would-be patients, and decline prenatal diagnosis if it is. The physician is likely bound under the informed consent doctrine to alert a woman at risk of the availability of prenatal diagnosis, but he or she is not required to perform it.³⁴ The choice to have prenatal diagnosis with the possibility of selective abortion is not only a matter for the woman's or the couple's conscience. As James Childress states: "The physician's conscience is also involved, and he or she is not legally or morally bound to violate conscience by providing amniocentesis (in contrast to providing information about amniocentesis) or by performing the abortion."³⁵

This still leaves us with the difficulty of those who may lie about their intentions at the time they seek prenatal diagnosis or, perhaps more likely, those who truly feel that abortion is not an option prior to prenatal diagnosis, but who change their minds under the weight of what can be crushing bad news.

To address this moral difficulty, we can probably do no better than to appeal to the traditional principle of double effect.³⁶ According to this principle one judges the moral acceptability of an activity having both good and bad results by reference to the following four considerations. First, the action issuing in mixed consequences must be either good or neutral in itself. Secondly, the good consequences must not follow from the bad consequence, i.e., it cannot be a case of evil as justifying means. Thirdly, there must be a reasonable proportion in the relationship of the good and bad consequences, a proportion which balances them or favors the good. Finally, though the bad consequences can be anticipated, they cannot be desired. This last subjective consideration can be measured by observing the actions taken to minimize bad consequences and avoiding them entirely when possible.

It would appear that one, two, and four are easily satisfied in the cases of opponents to abortion now providing prenatal diagnosis. Surely, the knowledge gained from these diagnoses is either good or neutral in itself. There are some risks in some of the procedures involved, but these seem small enough to allow the procedures themselves to be judged good or neutral. The good consequences of prenatal diagnosis do not follow from the bad consequences of any abortions which may result. The central good consequences follow from the treatment and preparation which early diagnosis of fetal defect allows. And, of course, those who oppose abortion do not desire that that consequence should follow from their good or neutral services. This can be measured by their disavowal of abortion at the outset of the doctor-patient relationship and by their attempts to provide counseling and other support services to those who must parent a defective child.

The most difficult factor to appraise is the third, that there is a reasonable proportion between good and bad results, a proportion balancing them or favoring the good. Obviously, when we are speaking of human life and its quality there can be no serious quantitative resolution of this question. We shall have to judge. Is the likelihood of producing some abortions balanced by the possibilities for good allowed now by prenatal diagnosis? It is my view that it is. There are exciting new possibilities in the area of fetal treatment. There are steps which can be taken, when one knows, to reduce the negative impact of fetal defect, physically at birth and emotionally before birth. Since most prenatal diagnoses are negative, these procedures may actually reduce the number of abortions which might otherwise have taken

place. Considerable parental anxiety is allayed by good diagnostic results. And, perhaps most importantly, a serious cultural rethinking of abortion may occur when more and more fetuses become our patients. These considerations incline me to think that the good of prenatal diagnosis now outweighs the bad. Thus, I conclude that though there are certainly serious, undesirable consequences not only possible, but likely, prenatal diagnosis now passes the tests of the double effect principle and is therefore an activity in which those who oppose abortion on moral grounds can participate and which they can support. Abortions which follow from prenatal diagnosis are lamentable, but they are not the responsibilities of those who have provided prenatal diagnosis, so long as those professionals have made their opposition to that result evident in word and action.

Clearly, the moral appraisal of medical technology is no easy task. Even when our commitment to an ideal remains stationary, the factual advances of medicine make for a continually moving target. An activity rightly condemned one day may have to be embraced the next, if the facts of the matter change. Prenatal diagnosis, I think, is just such an activity. Given a commitment to respect all human life, the fetus included, prenatal diagnosis was probably wrong yesterday, is probably right today. No doubt it will have to be reappraised tomorrow.

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7. This point is developed by Lebacqz, *op. cit.*
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