February 1971

Some Moral Problems Arising in Genetic Medicine

Paul Ramsey

Follow this and additional works at: http://epublications.marquette.edu/lnq

Recommended Citation
Available at: http://epublications.marquette.edu/lnq/vol38/iss1/5
golden age. I therefore congratulate the organizers of this conference for providing such an excellent forum for this discussion to take place.

REFERENCES


Dr. Ramsey discusses many of the moral and ethical implications of present genetic research. What are the hazards and risks to the human race engendered by unrestricted genetic manipulation? The interesting options and speculations which Dr. Ramsey presents should be of paramount interest to the medical profession and the general public.


Paul Ramsey is Harrington Spear Paine, Professor of Religion at Princeton University. He was for two semesters Joseph P. Kennedy, Jr., Foundation visiting professor of Genetic Ethics at Georgetown University Medical School.

Some Moral Problems Arising in Genetic Medicine*

Paul Ramsey

The aim of genetic medicine is to prevent the appearance of individuals with a genetic disease or to correct a genetic defect once the individual is in utero or following birth. Not all treatment of genetic diseases should be termed "genetic engineering" (which anyway is a bad metaphor) but only when the genes themselves are directly modified. Insulin injections, for example, are not a case of genetic manipulation, although diabetes is a genetic disease. When the site of the action itself is genetic in some future possible procedure performed on a gamete (ovum or sperm) or on its precursor cells to prevent the conception of defective individuals, on a conceptus whose genetic illness is identified by amniocentesis and interuterine monitoring or on an individual following birth will we have interventions that should be called "genetic engineering." The treatment of arginemia described by Dr. Wegman would be one such case.
As I understand it, one gene must be replaced by another, to manipulate out a bad gene entails the introduction of another genetic determinant. It may theoretically be possible to find a virus that would carry only the desired gene, or, known to carry no deleterious genes. In that case the moral objection about to be raised would not pertain. The immorality of the proposed trial would be supposed away.

However, the biophysicist, the late Leroy G. Augenstein, of Michigan State University, described the situation we actually face in deciding whether to begin testing genetic engineering on gametes. "Suppose we were to find a virus which carried the necessary DNA for correcting diabetes and made all the boys very tall (good basketball teams) and raised their IQ's by fifteen points (no flunking out of school)." Then if anything went wrong, it would be to be tragic, not an experiment we had done. Suppose, however, Augenstein continues, "we were unlucky and the virus contained not only a certain amount of DNA enabling people to make their own insulin, but additional DNA so that the group tested either went on to have defective children or developed schizophrenia. We would have a whole generation with extensive genetic changes before we even knew they were in trouble."

Obviously, if we knew beforehand that these would be the results, the introduction of a virus to correct the insulin production of an as yet unconceived child would be no proper treatment. It would rather be a wicked thing to do. But suppose we do not know that these terrible consequences of tampering with the gene for insulin would be forthcoming? What then? Is it only tragedy as a hazard of proper medical care if and when these things result? We should say not. Given the intricate and wonderful structure of the genes and the lottery that produces the genotype which is or becomes a human being, we ought moral-

ly to require a far higher degree of knowledge that there are no hazards of such gravity. It is not enough not to know, one must rather know that there are not these hazards before the homing-in on the gene for multiple could possibly be a choice worthy treatment of a hypothetical human being, as yet unconceived, whom seems likely to become diabetic.

This is not only because multiple injections are better treatment. Suppose diabetes was far more serious an illness than it is, and that the increasing number of diabetics arising from the gene pool is so very serious that something must be done about it. Still, we ought not to choose genetic engineering at any risk of producing individuals who may, in increased numbers, become schizophrenic in the first generation and who may be the mothers and fathers of children who are seriously defective in the second generation. We ought not to do this even if the defect corrected and the defect that might be introduced were equally serious. The reason for this conclusion is that there is a third alternative for treating the unborn child, we are not forced to choose between doing nothing about diabetes as an inherited disease and correcting it by genetic manipulation under the supposed conditions. The indicated treatment for preventing the transmission of diabetes would be having no children or fewer children. The treatment would be continence or getting married or using birth contraceptives at the same time or voluntary sterilization. Only someone who is more of a pro-natalist than the Roman Catholic Church ever was, or who strictly believes that every human being has an absolute right to have children, can avoid the conclusion that these are more choice-worthy options than the hypothetical child of a hypothetical diabetes gene.

Let us make the case a harder one, to see if these ethical conclusions or do not still hold true for the meaning of genetic responsibility. Suppose the bad gene believed to be manipulable by a virus is far, far more serious than diabetes, e.g., Huntington's chorea, where the defect will be passed on with a fifth-fifth probability. What, now ask, ought rightfully to be done in behalf of, first, the child prenatally and secondly, the hypothetical child preconceptually?

If amniocentesis, intraterine monitoring, etc., disclose the fact that an unborn child has two doses of the recessive genes for a serious illness or has proved unlucky on the fifth-fifth chances that he will be a victim of a serious dominant defect, without question his parents can rightfully consent to drastic prenatal treatments - since these treatments may, it is reasonable to believe, be beneficial to him. Then if the defect is really what it would be the tragic result of rightful actions. We could go further and say that even if the unborn child is not certainly afflicted with one of these diseases, it is better to change birth control measures than it is to have another population at grave risk. We could say that parents can validly consent in behalf of such an unborn child medically, permitting the physician to use possibly beneficial prenatal treatments that, however drastic, do not place the child at greater risk than now surrounds him as one of a specially engangered population.

It is obvious, however, that canons of loyalty involved in the treatment of an as yet unconceived life - canons of loyalty similar in any way to those of the loyalty of an actual child prenatally or postnatally - will require far more certainty of possible overall benefits to the hypothetical child before genetic engineering would be the treatment of choice. Such certainty is not possible in the first case of manipulating the genes of gametes. We would have already to know that a hypothetical child would not suffer worse mishap if relieved of the statistical likelihood that he will suffer, e.g., Huntington's chorea. To know this is not possible in the first trial. The trial would have to be redundant, or there would have to be no other alternative, for genetic manipulation of gametes ever morally to be done.

The truth is there are choice-worthy alternatives. We are not forced to choose between genetic engineering and doing nothing at all to prevent the conception and birth of these children. A hypothetical child is nothing - or at least nothing until we begin working on him preconceptually upon the fixed assumption that he will be engendered. Therefore, there would have to be at least no discernible risks before genetic surgery would be for him the treatment of choice. Before a child is at all actual he has no title to be born. Men and women, and especially the unqualified right to have children. It is simply not the business of medical practice to enable every marriage to produce a child by any means. The treatment for the prevention of serious genetic disease is continence, not getting married to a particular person, not having any children, using three contraceptives at once, sterilization, or trying them away to an old fashioned munsey!

In discussing the ethics of the crucial step that begins the trial of genetic engineering on human germinal material, we should demand to know why these alternatives are not more responsible genetically and in every other way. If some of these treatments of preference are inherently wrong, they are nevertheless less seriously wrong than in the first case exposing another human life to possible grave injury, not as an existing individual in his behalf medically and to which he cannot and cannot constructively be supposed to consent, for the sake of good to come to his parents, to science, or to other children to come. Finally, we must observe with some amazement that we live in an age that
can calmly contemplate these two contradictory procedures: (1) abortion when there is likelihood that the child will be seriously impaired mentally or physically, and (2) learning how to do genetic surgery on humans although this may lead to the conception of children who may be seriously impaired mentally or physically (the mishaps).

It may be unfair to attribute to those geneticists who write as if they are not to be deterred by a proper ethics of treating hypothetical children the pro-natalist attitudes of past traditional societies. If not, the explanation of their easy assumption that genetic engineering is a procedure which, when it seems feasible, should be put into actual use may be that for them genetic manipulation is only the currently visible small fraction of the very large iceberg dealing with the control of quality of human life generally, having in view mass improving self-modification. A subtle but significant shift has taken place from doctoring primary patients to noticing that non-patient, the human race. For this reason, patients now live even in the first and second generation may be passed over lightly, hypothetical children can be thought of as casualties to be improved at risk, and one can even contemplate permitting harm to come to them (with abortion as an escape for the injured) in the sake of knowledge and learning the techniques ordered to the good to come.

1. Come, Let us Play God.

**Childbearing In Families With Genetic Impairments**

Joyce M. Dwyer*

Recent developments and technical achievements in Genetics are intrinsically related and frequently find their basic application in the field of Human Reproduction. The transmission of human capacity and potential occurs with the conception of each new life. In Obstetrics and Gynecology, we are the most frequent observers of life's beginning. Our continued presence and care sustains and protects the mother and the infant while each new life continues its development.

For these reasons our responsibilities to the parents, the infant and society, weigh heavily upon us. Grave clinical and ethical issues—most of which are neither perceived nor appreciated by the average practitioner, let alone the unsuspecting public—result from the knowledge and technical expertise now available within the field of Genetics. Much of the subject matter comes under the heading of what has come to be called the "social problems" of human reproduction.

The purpose of this paper is to speak for the value of the life of the child, regardless of the degree or type of impairment present, or a human life's seeming lack of "perfection," and to plead for a worthy human response to parents possessing possible genetic abnormalities which may result in the giving of life to an infant with an impaired capacity to take full advantage of this most precious of all gifts—that of human life. It is important to understand that we now possess the potential to destroy our commitment to the value of new human life and its development of full human worth and capability. In fact, we have already begun. It is equally important to understand the rationale for a substantial portion of the momentum to apply genetic developments to the clinical problems of patients during the human reproductive process, and to suggest alternative, more constructive, positive directions for our human reason and energy.

If there is any question of where I stand and for whom I speak, my position is best exemplified by the words of Eugene Diamond, a practicing pediatrician and a member of the Illinois Child Health Committee:

_Miss Dwyer is an Associate Professor of Maternal and Infant Nursing (Obstetrics/Gynecology/Neonatology) at Boston College of Nursing, Chestnut Hill, Massachusetts._