The Linacre Quarterly

Volume 40 | Number 3 Article 15

August 1973

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The author, an associate professor of moral theology at Duke University, Durham, North Carolina, ponders some of the implications of man's expanding knowledge of genetics. This essay was given as one of the Boswell Lectures, at the First Methodist Church, Dallas, Texas, March, 1973.

We have come a long way s ce the initial observations of Gr gor Mendel in 1866, but we have yet a long way to go. If informati is only the first step toward ur er-standing, it probably does not is-represent the present situatio to say that we just now know ore about genetics and inheritance han we understand. The discover of the double-helix by Watson and Crick is only one instance of this generally applicable observa ion: we know a good deal abou the architecture of DNA and tha the keys to heredity, human dev lop-ment, and aging (and perhaps mind and memory) lie in the arr nge-ment of its atoms; but we do not yet understand the four-letter genetic code well enough to be able to *send* messages. We are at that rudimentary stage where we know (or think we know) the alphabet but cannot spell words with it, where we can intercept coded messages and sometimes interpret them, but we have yet some way to go before we can say that we master the mechanism.

Many believe (and the weight of the history of science is in their favor) that in due course we will learn how to read the messages already communicated within the double-helix, and between DNA and RNA; and when that is possible, we will likely be able to modify or edit or rewrite genetic instructions. Meanwhile, it is appropriate to assess what we can do technically and what we can do responsibly; and consider, in view of both present and future possibilities, whether we are able to do responsibly everything we are able to do technically.

Genetic mutations have already been induced in some forms of plant and animal life (notably fungi and fruit flies) but we have been cautious about producing permanent hereditary alterations in either the entire human species or a part of it. To this point at least, we have been both unwilling and unable (I hope not merely unwilling because we are unable) to accept Glanville Williams' implied challenge: "there is a striking contrast between human fecklessness in our own reproduction and the careful scientific improvement of other forms of life under man's control."[1]

Negative Eugenics

Part of the reason for not taking up this dare relates to technics: the "careful scientific improvement" of plants and animals has been thus far accomplished much more by negative, than by positive, eugenics. We have tried to "improve" some forms of life by selecting for certain desirable qualities and sacrificing certain other desirable qualities; but this has been mainly on the order of assisting "natural selection" rather than genetic engineering *per se*. My geneticist friends tell me that 23 allelic pairs on the 23 pairs of chromosomes can produce 8,388,608 (or 2^{23}) kinds of gametes in a single human fertilization. They tell me, moreover, that in view of the phenomenon called "crossing over" even this figure does not indicate the full extent of possible combinations in the gametes of a single individual: if there were only a single (not double or multiple!) crossing over in each chromosome pair, the gametes could contain 20 different combinations of derived alleles in one pair of chromosomes, or 20^{23}, or an incomprehensible 838,860,800,000,000,000,000,000,000,000! Perhaps that is why we worry a good deal more about the genes we inherit than the ones that got away! In any event, this is further evidence that we know much more than we understand and that we do not yet have an adequate theoretical basis for recombination of existing genes, much less a technology capable of affecting such a process.

More importantly in the case of human reproduction, there is a distinctly moral reason for refusing (at least for now if not *ubique, semper et ab omnibus*!) to accept this dare: human life, within the terms of Williams' formulation, is not yet generally thought to be one

of those "forms of life under man's control." Human life, in western culture and the Judeo-Christian theism within which it is grounded, enjoys special protections and rights which do not apply to other forms of life; and the protocols which guard human experimentation, valid consent, and the like have been formulated in acknowledgment of that presumption. Exceptions to this generally useful rule include the historical defenses of just war and capital punishment; still, in even these cases, the sanctity of human species life has been tacitly affirmed by elaborate discrimination of the classes of our life which are vulnerable to manipulation or aggression of this sort and by formal (if not always existential) awareness that it is *our* species life, and not some lower plant or animal life, over which we are venturing to exercise this dominion. And in recent years, the "exceptionable" status of just war and capital punishment has been called into serious question.

Genetic Future

Three methods have been proposed for modifying human genotypes and controlling our genetic future: eugenic engineering (through recombination of existing genes by directed control of conception) which would employ both positive and negative eugenics; genetic engineering (through surgical or antimutagenic chemical attack upon deleterious mutated genes) which would cause genes to "mutate back" or be eliminated; and euphenic engineering (through modification or alteration of gene action) which would regulate certain results f genetic disorder. All of these m - ods finally rest, presuming t r implementation, upon some agre - upon means for shaping our gen c future and, perhaps more import :- ly for our purposes here, some agr l- upon ends which are desirable or our genetic future. If I read e signs correctly, we do not now n- joy a consensus opinion on ei er of these points; and, until we o, it would be precipitate and i e- sponsible to undertake proced es which seem to be irrevers le. Meanwhile, we appear to be in the process of achieving an *e r- gent* consensus; and the rhet ric of ecology, of peace, and of m ni- mal standards of education, h is- ing, nutrition, income, poli cal participation, and all the rest, ay be inchoate ways of formul ng the conditions of that good fu ure which we want (and are in s me ways obligated) to bequeath to our sons and daughters.

Specifically, with reference to genetic inheritance, it is now thought that more than 1,600 human diseases are caused by de ects in the content or expressio of genetic information in DNA. Approximately 40 of these ca be diagnosed (with different cer ain- ties) *in utero* by chemical an lysis of amniotic fluid and cells an by examination of the morphol gical characteristics of chromosomal patterns. Among the diseases which can be identified by prenatal genetic diagnosis are erythroblastosis fetalis, hemophilia, phenylketonuria, cystic fibrosis, Lesch-Nyhan syndrome, and chromosomal disorders such as Down's syndrome and ploidy of the X and Y chromosomes.

Possible Choices

The entire list is impressive and further evidence that we now know some things, but not everything. What we know in these cases is that there are now some choices about genetic disease which, embracing both technical capacity and moral sensibility, we can make antepartum: (1) we can elect to terminate pregnancy (in cases, let us say, of cystic fibrosis which is among Caucasians the most lethal genetic disease of childhood); (2) we can try to correct the problem *in utero* (in cases, let us say, of Rh incompatibility); (3) we can elect to allow the birth and attempt to manage the disease postpartum (in cases, let us say, of phenylketonuria or hemophilia); or (4) we can resign ourselves to acceptance of an anomalous fetus and disadvantaged baby for which we can neither assess accurately the extent of damage nor provide specific remedy for the disease (in cases, let us say, of Down's syndrome). Each of these choices, of course, carries its own costs and benefits; and in all the variety of ways these can be calculated — in money, the allocation of scarce medical resources, parental pain and anguish, and fetuses who are not merely "yet unborn" but (depending upon our decisions) may be "never to be born." Not least among the questions to be raised about particular choices are "whose cost?" and "whose benefit?" since it is here that we confront the personal and social as well as medical and scientific ingredients in this decisional mix.

Most genetic diseases do not yet, however, present alternatives during gestation and in these instances our capacity for genetic engineering depends upon what we know through identifying carriers (by chemical analysis or phenotypic recognition) and calculating mating pair reproductive risks. In these cases we are faced not only with the management of affected persons but also with questions relating to reproduction by carriers, public health, genetic counseling, and the like. And it is at this juncture, I think, that some of the most perplexing and agonizing ethical issues emerge from our increasing capacity to control our genetic future. Here, especially, we are obliged to ask not only *what can we do* but what can we do *responsibly*. Sickle cell anemia is a genetically determined disease which may illustrate this aspect of our problem.

Sickle Cell Anemia

The allele Hb_1s is nearly absent in most human populations but it occurs in high frequency throughout a broad belt across central Africa and in lower or irregular frequency in countries bordering the Mediterranean and in India. Because the sickle-cell trait is thought to be a characteristic of many African populations, its presence in other locales is attributed to migration and/or interbreeding. Among Negro children in the United States, sickle cell is about six times more common than

the next most common long-term illness (diabetes), and the incidence at birth is estimated at 2/1,000 infants. Fifty thousand of the 22 million blacks in the United States are estimated to have the disease, and 2.2 million more are carriers who are capable of transmitting the anomalous gene to the next generation.

In homozygous affected individuals the allele is either lethal, ordinarily before reproductive age, or severely deleterious, and while varieties of care can be provided affected patients, there is yet no known cure. Among the symptoms are necrosis of various tissues, susceptibility to pneumonia, rheumatism from muscle and joint deterioration, heart disease, and renal failure. We know, moreover, that the mating pair risk for recessive genetic diseases is 25 percent homozygous affected, 25 percent homozygous normal, and 50 percent heterozygous carrier. Finally, present tests can accurately distinguish between those who carry the trait and those who are homozygous for the variant gene.

Now this is hardly an exhaustive treatment of all that is known about sickle cell, but it is enough to indicate that we have a good deal of information about the disease which in turn confronts us with alternatives for management that we would not otherwise have. The moral question, in its simplest formulation for the biblical theist, is what ought we do about sickle cell in view of what we know about it, our neighborly obligations, and God's intention for His creation? Should we do everything pos le for the person affected by s le cell? Should our efforts exten to carriers in order to discourage ir- riage and reproduction? C ht what we do be limited to ind d- ual patients? Ought there be p lic concern expressed in public ro- grams? These questions, and r re, reduce to two basic interests: er- sons and society, and the right nd obligations which are suppos to be appropriate to each vis-a-v the other.

Racial Undertones

That this disease is almos ex- clusive to blacks (about 00 whites are estimated to carr the sickling gene) only raises add on- al questions. In the 1970's, kle cell disease has become a na nal health concern of enormous ro- portions in this country. F eral budgeting for sickle cell pro ams has risen from one million 15 million dollars annually, a d a dozen or more states have ad pted legislation which requires s een- ing tests for the disease. B ause of the racial undertones an the social stigma that is likely o at- tach to carriers (for whom there is no remedy), some black l aders have called these program and laws discriminatory (because other ethnic predominating diseases — like Cooley's anemia among Ital- ians and Tay-Sachs among Jews — are not required by law for man- datory screening), threatening geno- cide (because child-bearing is inhib- ited), and useless (because there is no therapy for the carrier and only care for the affected patient). Sick- le cell presents an obvious exam- ple of a disease whose management entails urgent questions from many sectors other than those conventionally associated with scientific medicine. For most of these questions the hallowed unilateral doctor-patient relationship is simply insufficient. What, then, can we responsibly do or begin to do?

Some are already arguing that, in consideration of the survival of society, we may soon be obliged to make conception control — or that failing, birth control — mandatory for certain persons (or classes of persons) in order to limit the number of serious genetic defects in the general population. One medical school OB/GYN group, in a retrospective study of 35 HbSS and 15 HbSC pregnant patients, has viewed the gestations associated with these hemoglobinopathies so hazardous as to advocate "primary sterilization, abortion if conception occurs, and sterilization for those that have completed pregnancies. *Patients with sickle cell disease should be unhesitatingly thus counseled.*" [2]

But I wonder about such "unhesitating" advice. Apart from questioning whether *anything* in this area ought to be done unhesitatingly, or whether the presumption of a statistical morality is adequate warrant for a course of action — either of which is important in its own right and could easily generate a separate essay — it deserves asking whether these radical alternatives are currently indicated? whether this is what we can responsibly do?

Rights Involved

Compulsory programs for genetic screening, to say nothing of mandatory conception and birth control, already appear to encroach upon long-cherished rights to privacy; and if screening programs are coupled with (however subtle) coercion toward contraception or abortion or sterilization, it is arguable that certain protected reproductive freedoms are seriously infringed. Indeed, in consideration of the human values affirmed by and in this society — freedom, justice, the general welfare, and the secure possibility for development and achievement of persons — sickle cell, as a case in point, probably does *not* provide a warrant for compulsory programs of (in this case, negative) eugenic engineering. Even to require screening may achieve too little social benefit at too great a social cost.[3] A number of technical problems — e.g., diagnosing the disease in newborns, distinguishing homozygotes from heterozygotes, and being able to provide no cure but only care — attend screening. But there are also public problems — e.g., the stigma attached to heterozygous asymptomatic carriers which has reportedly affected employment and insurance eligibility — which further calls into question the need and appropriateness of mandatory screening.

Just now, at the nexus between facts and values in this matter, we are probably best advised to make available to all who want it full information about themselves and

sickle cell in order for them to decide for themselves what action, if any, they want to take. Public education and voluntary participation are the fitting emphases in testing procedures just now in order to avoid compulsion and the popularly prominent supposition that one racial group is somehow defective.

The benefits of this approach, of course, are not without their own costs: babies will still be born with this terrifying anomaly, children will continue to suffer through adolescence or early adulthood, and affected persons will be sick and commonly die before maturity. Still, in the long run of things, this price for human freedom and self-determination may be better paid than the costs to a humane society of massive assaults against this disease through mandatory screening, or compulsory abortion of fetuses which are at risk of being affected, or involuntary sterilization of carriers. Some of my black friends insist that being rid of sickle cell is subordinate to guarding their rights to freedom and self-determination.

I know, of course, that considerable energy (and not a little ink!) is being expended these days on some of the more exotic aspects of potential genetic engineering — *in vitro* fertilization, embryo implantation, cloning, and the like — and that some might think me irresponsible for failing to devote the bulk of this brief essay to matters of that sort. My apology for this apparent neglect is mainly owing to the sense of urgency with which other, more immediate, issues cl n my attention; and, closely rel d to that awareness, is the suspi n that we will not get very far d l- ing with unprecedented deve p- ments in human biology until ve can deal more comprehens ly and sensitively with anterior r li- ties.

Serious Questions

This is clearly not to su est that the ethical implications *in vitro* fertilization, for exar le, should not be an important m on our common agenda or at we should abdicate anticipati of the moral consequences of rti- ficial inovulation until the ro- cedure has run its course om laboratory experiment to rm birth. Some of my colleagues nd to view "new genetics" and ew biology" through the rose-c red twin lenses of optimism and ag- matism; but I continue to ink that some serious questions out both ourselves and the future ust be candidly asked, and mo -or- less adequately answered, fore we commit ourselves to doi ev- erything we seem to be tec ical- ly capable of doing. So I stil want us to consider whether ntra- uterine implantation of a l bora- tory conceptus is treatment of a disease or a woman's desire, whether artificial inovulation is in any sense human experimentation and if so whether it can satisfy the requirements for valid consent, whether an act of apparent compassion toward one generation runs serious risk of being an act of oppression in the next, whether anybody has a "right" to maternity, and whether our zeal for larger control of our reproductive capacities warrants running the risk of having a defective child. This is surely not an exhaustive list of the questions appropriate to *in vitro* fertilization and embryo implantation, but it is perhaps enough to indicate that the morality of a procedure is not fully assessed by either sole or primary reference to the accomplishment of technics or mere consequences. Indeed, the question of *who* will make these decisions is arguably more important than *what* choices will be made, since at least a clue to the latter will very probably be contained in the former!

I have wanted to argue here that the authority to make choices is proportional to responsibility for the choice made, and perhaps I can be allowed a personal anecdote as a single, simple illustration of the principle. When my wife was pregnant with our third child, we were made aware of certain genetic risks which, in turn, suggested to us the advisability of an amniocentesis. When we discussed this procedure with the physician, who was surely quite as aware as we were of the risks, he moved easily and gracefully from his role as scientific diagnostician to that of paternal reassurer: "You shouldn't worry; this is going to be a healthy baby; I wouldn't bother with doing a fluid tap." That's easy enough, I thought, for you to say; but who's going to have to live with this decision if it's wrong? who will be responsible for this baby if it is born with a serious genetic anomaly? and who will have to cope with all those other sets of relationships which ineluctably will be affected by a diseased or disadvantaged baby? So I just asked our obstetrician point-blank: "How much responsibility are you prepared to assume for this advice? How definitive for our choice in this matter is your opinion? Are we free to ask for a procedure that you think unnecessary?"

As it happened, the amniocentesis was done but none of the fluid cultured satisfactorily; and, perhaps because of the earlier conversation, we faced negotiating another contract — this time not about *a* procedure, but *the* procedure at birth which would (insofar as it was within our control) determine whether this baby would be respirated. That our obstetrician was eventually correct, and that we are the happy parents of a healthy and beautiful baby, does not at all diminish the utter seriousness of that decisional struggle. When our son is old enough to read this he may wonder about his parents, and their playing this kind of brinkmanship; but I hope he will also, by treating such agonizing choices seriously, begin to appreciate the tragic dimension of human existence.

Denial of Tragedy

The dominant attitude in Western culture, and therefore in Western medicine, has been a denial of tragedy. We have looked to the expansion and explosion of knowledge and technology to give us progressive control and mastery of

the world and ourselves, and we have supposed that there is no mystery which with time and human resource can defy an adequate and human resolution. Or, as Kenneth Boulding once remarked, our desire to conquer nature often means simply that we diminish the probability of small inconvenience at the cost of increasing the probability of very large disaster. In the measure to which this is so, we have undermined and repressed the human capacity for experiencing and affirming the tragic vision, or meaninglessness, or essential conflictedness of our life together.

So I think, especially in view of the excruciating and agonizing choices presented us by genetics and bio-engineering, that the struggle for mastery — which will surely continue — must be accompanied by an awareness of tragedy, an acknowledgment of the mystery of the reality of overwhelming human suffering. And that, I suppose, is precisely the place where ethical theory and moral practice most clearly employ and express the meaning of grace, as this notion has been developed in biblical theism and the Judeo-Christian tradition: grace, in this context, i he capacity to act decisively wit ut the self-justifying choices we w ld like to have had. I know, of co e, that this is a strange way to lk in a technocracy; but unles ve can discriminate between h ng to choose decisively among n- peting and ambiguous claims p- on us, and embracing choice le- finitively as though reason k ws nothing of sentiment nor righ of needs, we will have already di- cated the moral struggle and ith it an important dimension of hat it means to be men and w en and not gods.

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1. Williams, Glanville. *The Sanctity Life and the Criminal Law* (New Yor Alfred A. Knopf, 1957), p. 82.
2. Arthur T. Fort, John C. Morriso uis Berreras, Lemuel W. Diggs, and ew- art A. Fish, "Counseling the ient with Sickle Cell Disease about pro- duction: Pregnancy Outcome Do Not Justify the Maternal Risk!" *AM. Obstet. Gynecol.* (1971), 111:327. alics added.
3. What is being argued here shou not be construed as an objection all screening for genetic purpose For some appropriate guidelines, cf. Marc Lappe, *et al.*, "Ethical Social Iss es in Screening for Genetic Disease," *New England Journal of Medicine*, 296 129- 32, 1972.