Conflicts between Scientific and Humanistic Views of Genetic Manipulation

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by
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Introduction

I should like to begin my talk with a prefatory remark. The title of this paper, while accurate enough in indicating the general area of my concern, does not claim any comprehensive treatment for the paper of the conflicts between scientific and humanistic views of genetic manipulation. Rather, I want to focus on a cluster of concepts that continually operate in generic research counseling and therapy, whose analysis has been taken up only infrequently in the history of thought about medicine, disease, and the human condition. In the context of this symposium, those concepts cluster about the correlated notions of "genetic health" and "genetic disease"; they find expression in terms like "maladaptive trait," "chromosomal aberration," and so forth, and their positive correlates. And while the basis of my remarks—that theses are seen upon analysis, not to be purely descriptive terms but to involve strong valuational components—may come as no surprise to anyone here, it is sometimes worthwhile to take a fresh look *at* the seemingly transparent curtain of the obvious in hopes, perhaps, of finding some not-too-noble consequences lurking in its folds. Having laid some initial groundwork, we will be in a position to consider some of the ways in which scientific and humanistic views of genetic manipulation in humans may conflict.

The Fact/Value Distinction and its Application to Medical Contexts

The distinction between facts and values, between what is and is not so, and what ought and ought not to be so, has been around for a long time in philosophical circles—so long, in fact, that some think it an index of the lack of effectiveness of philosophy that the distinction has had so little impact on the lives of persons. For, we still value certain states of affairs and despise others, and think the facts quite justify us in doing so. But of course that as a criticism of philosophy is a mistake: it is not the intention or the expectation of those who espouse the distinction that thereby humanity can be transformed into purely rational beings.

Yet, for all that, the distinction does get collapsed or ignored and frequently goes unnoticed in human affairs. Usually this is relatively innocuous, occasionally irritating, and sometimes amusing. (You will perhaps recall Bertrand Russell's pejorative conjugation: "I am firm; you are obstinate; he is a pig-headed fool.") As one philosopher has observed, "The motive power of a value judgment is often greatly increased when it appears in the rationale of those who hold it not under its proper logical flag as a value judgment but in the disguise of a statement of fact."[1] When the conflation of fact and value becomes *ideological* and values are masqueraded as facts and thereby employed as "objective" justifications for policies of sweeping social consequences, considerable mischief can result. Nor does abuse of the distinction necessarily involve ignorance of it; the distinction itself may be used as a tool of oppression. One bestows a kind of objective irresistibility upon an approach to human affairs in labeling it and regarding it as "scientific" and "concerned only with factual matters" while perhaps explicitly acknowledging the fact/value distinction. We need perhaps only to be reminded

of the critiques by Thomas Szasz of the psychiatric labels of textbooks of clinical psychology and forensic medicine to realize that, in some eyes, giving voice to the distinction is perfectly compatible with violating it systematically.

Over the past decade, the movements giving rise to the critical studies of the social sciences of the previous 30 years (by Mannheim, Weber, Parsons, Wootton and others), have come to focus upon medicine. Peter Sedgewick, in a recent review and discussion of the contemporary status of the sociology of medicine, has argued for viewing:

> the character of illness and disease, health and treatment, as social constructions . . . . Outside the significance that man voluntarily attaches to certain conditions, *there are no illnesses or diseases in nature*. . . . The medical enterprise is from its inception value loaded; it is not simply an applied biology, but a biology applied in accordance with the dictates of social interest . . . . Out of his anthropocentric self-interest, man has chosen to consider as "illnesses" or "diseases" those natural circumstances which precipitate the death (or the failure to function according to certain values) of a limited number of biological species: man himself, his pets and other cherished livestock, and the plant-varieties he cultivates for gain or pleasure.[2]

For example, we are all familiar with the ravages of Dutch Elm disease; but had the identical organism infected only some common species of desert succulent, we would regard it (if we even noticed it) merely as a competition of two species.

But it is not merely the undesirable aspects of the objects of human interests that constitute the spheres of application of the concepts of disease and illness. As Sedgewick puts it:

> *All sickness is essentially deviancy.* That is to say, no attribution of sickness to any being can be made without the expectation of some alternative state of affairs that is considered more desirable. In the absence of this normative alternative, the presence of a particular bodily or subjective state will not in itself lead to an attribution of illness.[3]

For example, the Rockefeller Sanitary Commission on Hookworm, in 1911, found that "affliction" with that particular parasite was regarded as a part of normal health in some parts of Northern Africa.[4] And, in one South American Indian tribe, what we regard as the disease of *dyschromatic spirochetosis*, characterized by the appearance of colored spots on the skin, was so much the common, normal state of members of the tribe that its absence was thought to be a pathological state of such severity that a strong taboo existed against marriage of those without the spots.[5] For that tribe the absence of the spots was a disease state, and given their elemental apprehensions about how it might be propagated, the absence of the spots would count as a heritable disorder, just as we would count the presence of the spots as a genetic disorder.

Sedgewick's remarks constitute important observations about the basic tendencies behind the classification of an organism's state as a disease or illness: such classification, generally (1) is made only for species in whose continued existence or constant function we take an interest; (2) is made only for states of those species that deviate from recognized norms in a disvalued way; (3) is made only for states of those species for which our present network of explanatory laws and concepts holds some promise of positive alteration and control. However, there is more to the involvement of values in medicine than interests and norms. Consideration of some recent work on the notion of "genetic health" will advance our inquiry.

"Genetic Health" an Elusive Concept

Marc Lappé has recently considered the question of who the genetically health really are.[6] His procedure was to articulate a number of functioning, plausible definitions and to show of each that it includes some individuals we would want to regard as diseased and excludes some that we would want to regard as healthy. But I found his discussion interesting not so much for what he showed about the difficulty of defining "genetic health" as for what it showed about the decision to describe some state or trait as a disease due to a genetic factor rather than to some external one.

Consider a plausible, widely-used definition of health. Genetic health consists in the state of being free of genes or chromosomes capable of causing clinically significant disease or disability in the individual possessing them. Despite the simplicity and intuitive appeal of this definition, it appears to be unsatisfactory.

First, it overlooks the role that external factors play in the occurrence of many genetic diseases. For example, there is an X-chromosome-linked gene for a sugar metabolizing enzyme known as "G6PD." Carriers are healthy to all appearances until and unless they are exposed to any of a variety of drugs (including aspirin), or certain foods (such as the common broad bean, *Vicia fabia*). Upon exposure, carriers of the gene contract a serious blood anemia. Here is a case where it is the presence or absence of some external factor that is as much a determinant of the onset of the disease as is the genetic trait. Similar relationships exist between genetic and environmental determinants for phenylketonuria, diabetes, even *Xeroderma Pigmentosum* cancer of the skin: in all of these cases, in the absence of the critical environmental factors one is "free of genes capable of causing clinically significant disease."

Second, the definition is silent on the question of whether a heterozygous carrier of a recessive gene, such as that for sickle cell anemia, is healthy or not. In the heterozygous state, a carrier has relatively little personal risk (again, depending upon environmental factors: carriers occasionally have some trouble with altitude) from the trait, and may enjoy a virtual immunity to malaria.[7] But in the homozygous state, the resulting anemia is severe, painful, progressively debilitating, and frequently involved in an early death, and the malarial resistance is lost. Thus, a pair of heterozygous carriers is at risk for homozygous children. One might say that there is a latent risk manifested in the presence of a mate of a certain genetic makeup, for producing children with the sickle cell disease. Similarly, the recessive gene for Tay-Sachs disease may be heterozygously transmitted for generations without apparent effect, until transmitted homozygously; death due to neurological degeneration is inevitable and occurs early in the childhood of homozygous Tay-Sachs children of apparently healthy heterozygous carriers. In these cases we have latent risk, manifested only under certain "external" conditions, either the presence in the environment of the individual of a triggering or threshold condition, or the presence of a similar gene in the fertilized ovum.

The obvious response would be to revise the definition so as to include heterozygous harriers of deleterious recessive genes, so that genetic health consists in being free of genes or chromosomes capable of causing clinically significant disease or disability in either the heterozygous or the homozygous state. And here an even more astonishing fact emerges as relevant. Morton, crow, and Muller[8] have calculated that the number of such genes carried recessively by each and every person averages between 3 and 5. Cavalli-Sforza and Bodmer[9] concluded that "almost everyone carrie[s] the equivalent of more than one lethal recessive gene." Hence, under the amended definition, it is unlikely that anyone is genetically healthy.[10]

There are other suggestive examples. Lappé reports that one gene has been

found that is responsible both for a particular immunologic ability and also for susceptibility to a virus that causes a form of leukemia. The gene for type A blood appears to afford its carriers some resistance to duodenal ulcers, but predisposes them to infection with smallpox. In the former case, were the cancer-causing virus non-existent, the gene would be wholly beneficial. In the latter case, one who carries this trait would have been poorly adapted for survival during the great smallpox epidemics prior to the development and general availability of Jenner's vaccine; but the same trait now has some positive survival value in industrialized societies characteristic in their ulcer-contributing stress.

These examples suggest that a great deal (if not all) of human disease and disability has genetic components. This, in turn, raises the question of whether the classification of a disease etiologically may well have involved a (perhaps unwitting) preference for environmental over genetic components, and that previous etiological classifications may require revisions as our knowledge of genetically-determined susceptibility increases. But the other side of the coin is what I wish to emphasize here: environment, broadly construed, plays an important contributory role in many diseases classified as genetic in etiology; our perceptions concerning alternative ways of dealing with those diseases *may* thereby be illicitly limited to standard techniques of genetic manipulation, such as amniocentesis and therapeutic abortion, *in utero* biochemical supplementation, or artificial insemination donor techniques. I am suggesting that euthenics, the study of environment modification as a means of treating or avoiding what we call genetic disease, should receive greater attention than it now enjoys. Shortly I will speculate why the great preponderance of work on these diseases seems directed toward genetic engineering, rather than environment modification—why environment modification isn't regarded as a viable approach to certain diseases, whereas negative and positive eugenics is.

One final definition of "genetic health" considered by Lappé will furnish the opportunity to lay out a few additional facts for our attention. From a population point of view, an individual might be considered genetically healthy only so long as his genotype was not a significant threat to future generations.

Besides what now may strike us as obvious problems concerning our ability to determine what will be the preferences and aversions of future generations, environmental changes have occurred in the past and doubtless will occur again in the future—changes that result in survival value accruing to previously deleterious genes, and survival disvalue accruing to previously beneficial ones. Our greatest safeguard for the future of the population would seem to lie in the richness of human genetic diversity *per se*. Lappé concludes:

> As long as this diversity exists, *there will be genetic disease and disability* due to the chance coming together of the same deleterious recessive genes and from the random assortment of genes which are adaptive in combination with one genotype and maladaptive with another. Thus, the greatest paradox of the concept of genetic health is that while from a population point of view, the "healthiest" individuals are probably those who carry the greatest number of genes in the heterozygous state, they are also the ones at greatest risk for transmitting genetic disease.[11]

The point worth noting here is that the public mind has seized upon the false, normic notion that genetic health (understood as the absence of potentially or actually deleterious genes) is enjoyed by all save a few individuals, and the other false notion that the future of the species would best be served if somehow such deleterious genes could be eliminated. People's tolerance for what they perceive to be defectiveness in heterozygous carriers has been low. If public reaction to advances in genetic manipulation is to be well-reasoned, those advances must be viewed and represented against a background of knowledge that includes these

three facts: (1) All of us are heterozygous carriers for recessive genes capable of causing disease in the homozygous state. (2) The adaptability and resilience of our species turns upon our genetic diversity and homogeneity, which carries with it the potential for genetic disease. (3) In general and with a few exceptions, oneself or one's offspring being at risk for a genetic disease is essentially an environmental concept, meaning that risk probabilities vary with environmental context and are not constant with the individual.[12]

A Try at Defining "Genetic Disease" and "Genetic Health"

An integration of the results of our examination of the above facts about disease generally and genetic diseases in particular suggests the following five-point analysis of "genetic disease and "genetic health." (1) A genetic disease involves a species in the welfare of whose individual members we take an interest. (2) a Genetic disease involves a state or item of behavior of some of those members that deviates from recognized norms of appearance and behavior. (3) A genetic disease involves such states or items of behavior as are generally disvalued under the dominant value structures of the society. (4) A genetic disease involves only such states and items of behavior for which our present network of explanatory laws provides an identifiable genetic etiology. Finally, (5) a genetic disease involves only such states and items of behavior for which the present or foreseeable genetic technology holds promise of alleviation or avoidance. Genetic health, then, may be defined as the absence of genetic disease as determined by joint satisfaction of all five of the listed criteria.

Several features of the notions under the present analysis bear specific comment. First of all, the notion of genetic disease has been relativized in a number of ways—to species of interest, to current scientific theory, and to current and foreseeable technology. In turn, each of these, *including* current scientific theory and technology, is value-laden. I will sketch some arguments for this last claim in the following pages. But given that pervasive lacing of value throughout every aspect of our criteria for genetic disease and genetic health, we must conclude that these notions are fundamentally moral in character. Finally, insofar as the medical terms we began with—"maladaptive trait," "genetic abnormality," "congenital malformation," and the like—function in contexts of sweeping social consequence as tough they were descriptive, factual terms, they are ideological. It needs to be shown how these contentions follow from the proposed definition.

One consequence of my proposed definition is that whether a state is a disease or not depends upon recognized norms of appearance and behavior, and upon the values placed on approximating such norms. Thus, one way of treating some genetic diseases would be to change people's attitudes about them. Given a genetic etiological component, the absence of colored spots ("suffering," from *our* point of view, from *dyschromatic spirochetosis*) is as much a genetic disease as the presence of those spots in an individual in our society would be. It is to be presumed that such a tribe's culturalization and increased interaction with other societies would "cure" their members who presently "suffer" from "having no spots," and may "afflict" the spotted ones.

Another consequence of the definition involves the fact that a state's being a genetic disease turns upon the "dominant values" of a society. The notion of "the dominant values" is difficult, if understood in terms of democratically-determined transitive rankings of personal preferences. Work done by Kenneth Arrow[13] indicates that it is impossible to construct a rule for aggregating personal preferences that satisfies various reasonable, humanitarian requirements, including personal freedom of choice among alternatives, responsiveness to changes in personal preference, and ability to generate transitive social rankings. What this suggests with respect to the classification of certain states as genetic diseases is the following; (1) such classification contains rules for aggregating

personal preferences; (2) such classification, for that reason and because of Arrow's theorem, cannot remain democratically responsive to changes in personal preference; (3) insofar as it involves *covert* entrenchment of preferences, such classification conflates facts and values and is thus *ideological*; and (4) insofar as the preferences thus entrenched are not even initially obtained through legislative or other democratic, representative sampling of public preferences, such classifications are elitist in ideology. Thus, as things now stand, declaring a state a genetic disease involves regulating public attitudes by imposing what may be only elitist values through application by the medical science community of value-laden terminology as though it were purely descriptive and factual.

This has suggested to some of a more radical turn of mind, in the scientific community as well as elsewhere, that the technology of genetic manipulation poses perhaps the greatest threat yet in the arsenal of those sectors that seek the amassing and wielding of power. Any review of the history of attempts at "improving" humankind through selective breeding (and perhaps other forms of genetic manipulation) reveals the likelihood that two factors, neither having to do with the well-being of specific individuals, have determined the aims of those attempts. These are: the available technology of the time, and the dominant social-economic-political structure. For example, the selective breeding of slaves in the antebellum South represented both the available technology, consisting in the selection of desirable phenotype characteristics and their attempted conjunction in sometimes forcibly bred offspring, and the dominant social, political, and economic structure: the agricultural economy that regarded blacks as less than human exploited their importation, sale, breeding and use as slaves, virtual beasts of burden, under the political sanction of the states and the social approval of many whites. The cases of Nazi eugenics, the European eugenics movements of the nineteenth and early twentieth centuries, and the use by a rubber company in Brazil of a combination of genocide and stud farms to breed slave labor, all display similar patterns.

If these generalizations hold in the present era as well, our prospects are bleak. For, we seem rapidly to be approaching a state of technological development when available technology will make a great deal, if not everything, possible in genetics. Further, if (as history's lessons suggest) the guiding objectives of controlling elitist structures will be the protection of society's existing class structures, the maintenance of political superiority internationally, and the continued maximization of profit, the applications of technological advances in genetics will be directed to serve those ends.

For example, the question of why research in genetic engineering, rather than environmental manipulation is favored in funding decisions would be answered on this radical view of the social role of science and technology as due to the vested interests of large corporations in maintaining widespread use of carcinogen-producing agents.

Ethan Signer (Biology Department, Massachusetts Institute of Technology) writes:

> Power is exercised by the dominant minority principally in the ever-expanding development of technology. The main result is to widen the gap between the managerial and the weaker sectors, so that technology functions more and more in the interests of the managerial and only incidentally primarily to support technology . . . . The way science is used is determined by the interests and orientation of the dominant social sectors, and there is no reason to expect this to be any less true for gene manipulation than other research. [While] therapeutic applications . . . will . . . be developed, . . . according to the present pattern[s of health-care delivery] such benefits will be controlled by and available mainly to the dominant sectors . . . . And it is virtually certain that any applications with a potential for

> exploitation, weaponry or any other means of social control will also be developed and most probably used for just that purpose.[14]

I quote Signer for two reasons. It is important, I think, in considering the question of what values genetic disease and its treatment involve to look at some extreme, but to many plausible, views of the social roles of medical science and technology. Second, while I remain not fully convinced by Signer's interpretation of the relation of science, technology, and power (science existing for the purpose of technology, technology for the purpose of social control), I *am* struck by what appears to be a methodological interrelationship, which brings me back to the original theme of this paper, conflicts between scientific and humanistic views of genetic manipulation.

There is an extremely prevalent view of scientific knowledge and understanding and its confirmation, focusing sharply on this potential for conflict. I first encountered the view when, over a luncheon discussion of the application of statistics to human behavior a prominent statistician said, "You have not explained a phenomenon until you are able to control it." But since then I have encountered the view repeatedly. Leon Kass says:

> Power . . . is . . . an important *validation* of knowledge. One definitely knows that one knows only if one can make. Synthesis is held to be the ultimate proof of understanding.[15]

P. Handler has observed:

> One of the acid tests of understanding an object is the ability to put it together from its component parts. Ultimately, molecular biologists will attempt to subject their understanding of all structure and function to this sort of text by trying to synthesize a cell. It is of some interest to see how close we are to this goal.[16]

It is thus easy to view the development and application of technology as a requirement of good scientific practice, whatever its social consequences may be. But this fact virtually insures a collision between scientific and humanistic views of genetic engineering. For, the humanistic values of personal freedom of informed choice among alternatives, applied to the direction and use of genetic research and experimentation through legislative and public funding decisions, may deny to genetic science those very applications of technology (as in asexual reproduction by cloning, genetic synthesis, and cellular engineering) that would provide validation of its theories.

Conclusion

What I have been leading up to can now be stated compactly. The ethical questions being raised today concerning the genetic manipulation of humans are *not* properly viewed as external issues involving possible immoral uses of the knowledge developed by a value-free science of human genetic disease. Rather, they are questions raised concerning (a) the implicit values behind the decisions in virtue of which medical science is taking the genetic turn, and (b) the value conflicts which must arise between the scientific view of genetic manipulation and the humanistic view of it. They are demands that therapists and counselors recognize that hidden values may underlie and guide the decision to call a particular individual maladapted to his environment, rather than call the environment maladapted to that individual. They are demands for rehumanizing the application of science to humanity's estate—even at the expense of proper scientific values.

Let me repeat the closing remarks of Leon Kass's article as my own:

> In the *long* run, our hope can only lie in education: in a public educated about the meanings and limits of science and enlightened in its use of technology; in scientists better educated to understand the relationships between science and technology on the one hand, and ethics and politics on the other in human beings who are as wise in the latter as they are clever in the former.[17]

Notes

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[1] Gustav Bergmann, "Ideology," *Ethics* 61 (1951): 205–218.

[2] Peter Sedgewick, "Illness—Mental and Otherwise," *The Hastings Center Studies*, 1, no. 3 (1973): 19–40; quotation at 30–31.

[3] Ibid., 32.

[4] Cited in A. L. Knutson, *The Individual, Society, and Health Behavior* (New York: Russell Sage, 1965), 49.

[5] David Mechanic, *Medical Sociology* (New York: The Free Press, 1968), 16.

[6] Marc Lappé, "Genetic Knowledge and the Concept of Health," *The Hastings Center Report* 3, no. 4 (1973): 103.

[7] Cf. comments by Arno Motulski in the discussion of Paul Ramsey's "Screening: An Ethicist's View," pp. 162–163, in *Ethical Issues in Human Genetics*, ed. Bruce Hilton et al. (New York: Plenum Press, 1973). One autopsy study found no difference among normals and sickle cell trait carriers (heterozygotes) coming to autopsy, suggesting no differences in mortality. Another prevalence study in California of sickle cell trait at various ages showed no difference in frequency of occurrence.

[8] Morton, N. E., J. F. Crow, and H. J. Muller, "An Estimate of the Mutational Damage in Man from Data on Consanguineous Marriages," *Proceedings of the National Academy of Sciences* 42 (1956): 855–863.

[9] L. L. Cavalli-Sforza and W. F. Bodmer, *The Genetics of Human Populations* (San Francisco: Freeman, 1971).

[10] James F. Crow has estimated (personal communication) that the probability, given random meeting, of a couple being capable of transmitting some lethal gene homozygously to their children is much less than 2 percent.

[11] Lappé, "Genetic Knowledge and the Concept of Health," 3.

[12] This is not to say that genetic disease is unavoidable, but only that an inherent risk for it is. If individuals had full knowledge of their lethal recessive traits, selection of mates might well include considerations of genetic compatibility. More likely, socially-accepted options for couples at risk may include artificial insemination-donor, artificial inovulation-donor, or even gonad-transplantation.

[13] Kenneth J. Arrow, *Social Change and Individual Values*, 2nd ed. (New Haven: Yale University Press, 1963).

[14] Ethan Signer, "Gene Manipulation and the Role of Science," in *Readings on Ethical and Social Issues in Biomedicine*, ed. Richard W. Wertz (Englewood Cliffs, N. J.: Prentice-Hall, 1973).

[15] Leon Kass, "The New Biology: What Price Relieving Man's Estate?" *Science* 174 (1971): 779–788.

[16] P. Handler, ed., *Biology and the Future of Man* (New York: Oxford University Press, 1970) 55.

[17] Kass, "The New Biology," 787.