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ESSAYS

GENETIC THERAPY: ETHICAL AND RELIGIOUS REFLECTIONS*

James M. Gustafson **

To write a brief history of the discussions of ethics and human genetic research and therapy is something of a temptation, but one to be overcome. All that is needed is a reminder of the publications edited by Michael Hamilton, the conferences on ethical issues involved in recombinant DNA research and the subsequent NIH guidelines, the project of the Hastings Center funded by the NIH,¹ the numerous papers by persons who were clinically involved in genetic research and therapy, the contributions by a number of authors from the fields of ethics, law, and theology, and the changes in judgment by significant persons in biological sciences about the moral risks involved. After more than twenty years of reflection and publication, whether there are some truly new issues for ethics and religious thought to deal with is an open question. Deeply involved in discussions in this area two decades ago, preparations for this paper mark a return of my attention to an area that had been subordinated as a result of other projects and interests. I am loathe to contribute to the redundance in the ethical literature.

Many new factors have come into being in the genetic research and therapy field during the last several years. There is new knowledge about human genetics, and with the Human Genome Initiative this will expand at a dazzling rate. As a result of this knowledge new opportunities for therapeutic interventions have developed. There is a new moral and public consciousness about therapeutic research in its experimental phases and a notable sensitivity and sophistication about ethical issues on the part of many

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1. The papers from this project are found in ETHICAL, SOCIAL AND LEGAL DIMENSIONS OF SCREENING FOR HUMAN DISEASE (Daniel Bergsma ed., 1974).

investigators. While some investigators might still feel that the authority of regulations is a restraining externality, for many the ethical sensitivity and sophistication is clearly a matter of internal conviction and importance. We now have institutional frameworks both within the government and in the private sector which bring research and clinical experimentation into steady interaction with legal, ethical, and public concerns. Some lawyers, theologians, and philosophers have learned enough science to grasp the specific quandaries faced by researchers and clinicians, and some of the latter have learned to use the vocabulary of ethics. Dr. French Anderson's publications are clear evidence of participation in this wider context of deliberation.

The starting focus of this presentation is Dr. Anderson's publications, authored individually and in collaboration with others, that include concerns for ethics.² Beyond this focus, various considerations come to the fore; an expansion of the context makes this possible. If there is any increment of novelty in this presentation, it will be small; Dr. Anderson has engaged literature written by persons whose work is similar to mine. Maybe some margins of reflection can be extended in a fruitful way.

HOW ETHICAL ISSUES ARE FORMULATED

As an initial matter, it is necessary to construct a pattern of how Dr. Anderson and other genetic therapists come to formulate the ethical dimensions of their activities. First, some comments on how they do not. They are not natural, from which they draw inferences about the moral or religious legitimacy of certain interventions. Though they have background beliefs about the human being as part of the evolutionary process, these do not dictate or determine their particular choices. They do not ordinarily come armed with a single-minded ethical theory that they adopted as a result of their studies of moral philosophy—a theory that can be applied rather deductively to each case at hand. They have been exposed to such theories, of course, which are reflected in their view of ethical dimensions, but normally are not adherents to a single ethical theory. They know that they are dealing with the large and frequently debated issue of what constitutes the distinctiveness of the human being and what is the good, or are the goods, of the

2. For the purposes of this Essay, it is sufficient to focus on the following articles: W. French Anderson, *Genetics and Human Malleability*, HASTINGS CENTER REP., Jan.-Feb. 1990, at 21-24 [hereinafter Anderson, *Malleability*]; W. French Anderson, *Human Gene Therapy: Why Draw a Line?*, 14 J. MED. PHIL. 681 (1989) [hereinafter Anderson, *Draw a Line*]; W. French Anderson, *Human Gene Therapy: Scientific and Ethical Considerations*, 10 J. MED. PHIL. 275 (1985) [hereinafter Anderson, *Considerations*]; W. French Anderson & John C. Fletcher, *Gene Therapy to Human Beings: When it is Ethical to Begin*, 303 NEW ENG. J. MED. 1293 (1980).

Put even more formally, the steps seem to be answers to the following questions: 1) What can be done now given current knowledge conditions? 2) What ought to be done now given this knowledge, and what reasons justify that? 3) What, in various scenarios of the future, are genetic therapists likely to be able to do? 4) What, in the light of present factors, scientific, ethical, and public responses, should and should not be done in each of those scenarios? 5) What reasons are given for both authorizing and limiting possible interventions?

Different reasons or evidence are offered to justify these questions. First, there is evidence of scientific knowledge conditions—current ones, those on the immediate horizon, and those that are probable in the more distant future. Second, there are ethical reasons derived from the current literature and what is acceptable to an informed public. These include boards and committees that must review all research proposals, *e.g.*, informed consent by the patient or a suitable surrogate and risk-benefit analysis with a judgment in favor of the benefits. They also include fairness or justice in access to therapy, the value of liberty which rules out coercive use, and concerns for various human goods—those that warrant therapy, those that do not, and those that are now ambiguous. Third, there are appeals to what the public will approve. And finally, there are larger beliefs about the human being—what ought to be valued about human life (appeals to dignity, etc.) that are belief conditions on which there is not complete agreement. The analysis of Anderson's ethical articles continues by eliciting the judgments made, proposed, or left open in each of these types of evidence.

First, regarding *scientific knowledge conditions*, the standard procedures for preclinical trials are clearly necessary conditions. The judgment of when to begin clinical trials is acknowledged as one involving probabilities of success, but in the case of a tragic and lethal disease "it would be just as inappropriate to delay treatment of patients while we are awaiting long-term results in primates as it would be to rush into experimentation with patients before studies of small animals have been completed."³ Since genetic science is rapidly developing, the choice about which therapies to use on humans, and under what conditions, is an open, developing issue.

When the discussion moves from somatic cell therapies to germ-line, the knowledge conditions must be specified differently. "It would require that we learn how to insert a genome not only into the appropriate cell of the patient's body, but also how to introduce it into the germ line of the patient in such a way that it would be transmitted to offspring and would be func-

3. Anderson & Fletcher, *supra* note 2, at 1229. See also Anderson, *Considerations*, *supra* note 2, at 278.

human being. These are the objects of their theories. They are somewhat perplexed, as are most of us, about how health as a human good is related to other aspects of the human good, *i.e.*, in what ways is it a condition for other aspects of flourishing or whether it comes near to being an end in itself. But, as Dr. Anderson's questions in his articles indicate, they do not have a simple coherent vision of the human good.

In one sense, the process genetic therapists engage is akin to the following. New knowledge coming from basic research gives insight into the causal factors involved in a genetically based human disease. Thus, the possibility of new therapeutic interventions emerge. For both scientific and moral reasons, as Anderson and colleagues make clear, there has to be a sequence of laboratory research prior to the first use of a genetic procedure on humans. With the best evidence in hand, there is recognition of the risk factors to human patients, and every bit of knowledge and care is used to minimize this risk and to maximize the desired healthy outcome. They adhere to the voluntary principle; properly informed consent of the patient or a proper surrogate is given. Distinctions are made about the purposes and the biological conditions of genetic therapy; radical eugenics is ruled out; enhancement therapy is at a minimum questionable; germ-line intervention might be justifiable in the future, but caution about this therapy is communicated; somatic cell therapy is sound given the accuracy of specific knowledge conditions for a particular disease.

They then proceed with cautious confidence to prepare a protocol that is justified by the scientific knowledge, the severity of the disease, the assessment of risks and other moral considerations, and the indication of the particular patient or patients for the experimental therapy. Their follow-up procedures are clear and precise and their monitoring practices are insurance against both clinical and moral negligence on their part. They do not promise complete cures, but high probabilities of improved health. Thus, medically and ethically, they venture into an uncertain future; fallibility is recognized, but the evidence supports a critical judgment that the intervention is worthy, when a whole range of considerations are taken into account. They have decided that a particular intervention is good and right, both medically and morally. Because of the nature of their vocation, the focus of medical and ethical attention is on a particular act or a class of acts. The normal conditions of moral responsibility have been met, given certain background beliefs and assumptions of our culture and institutions. What can be done, in the case at hand, ought to be done. Somatic cell genetic therapy, given proper knowledge conditions, ought to be undertaken. But there are some interventions that, at least for the present, ought not to be done.

tional in the correct way in the correct cells in the offspring.”⁴ As of 1985, the technique of microinjecting a fertilized human egg was not acceptable for three reasons: (1) the procedure had a high failure rate (implying that a low enough failure rate might make it appropriate); (2) it could produce a deleterious result (implying that when such a result can be avoided it might be appropriate); and (3) it would have limited “usefulness” (again implying that when it would have greater usefulness it might be appropriate).⁵ We will cite the ethical question of this technique below.

The knowledge conditions for some enhancement therapies appear to be in place, and, as human genetics develop, more possibilities of these therapies will increase. The ethical questions raised by Anderson about enhancement therapy are intertwined with the knowledge conditions requiring further discussion hence. More immediately, the principal questions are what constitutes a disease and what constitutes prevention rather than enhancement.

Second, what *ethical considerations* are brought to bear to support judgments? As noted, Anderson affirms the standard conditions that review committees must evaluate—a favorable risk-benefit ratio and consent by the patient or a proper surrogate. In cases of lethal diseases when experimental therapy might be done without the scientific certainty normally required, the possible preservation of life overrides normal constraints. The ethical thinking is somewhat similar to thinking in the just-war tradition; after all non-violent means to settling a dispute have been attempted, and given the conditions of a just cause, violence might be reasonable. The medical ethical warrant implied by Anderson is not new; the crisis of impending, but possibly avoidable, death warrants extreme measures. One is impressed, however, by the careful assessment of the risks and the acknowledgment of the seriousness of the medical judgment that must be made.

The ethical questions Anderson raises about germ-line therapy imply his consideration of several values and concerns. One is the irreversibility of outcomes; an inherited change could perpetuate any mistake. Another is unanticipated outcomes. At this point the Catholic moral theological procedures of the principle of double (or multiple) effects might be invoked.⁶ A stringent response can be inferred, or is at least suggested, by Anderson. Any germ-line therapy ought to be restrained until there is a high probability that presently unforeseeable deleterious outcomes will not occur. This would apply even if the foreseeable outcomes were beneficial to the patient

4. Anderson, *Considerations*, *supra* note 2, at 283.

5. *Id.* at 285.

6. Indeed, something like this procedure of reasoning seems implied in other of Anderson's moral evaluations.

and progeny. One is not quite sure how Anderson would deal with this since it is raised as a critical ethical *question* and not precisely answered.⁷

The conditions which warrant enhancement therapy "could be justified on grounds of preventive medicine."⁸ His well-chosen example relates to arteriosclerosis, and the case for undertaking this therapy is strong unless some alternative therapy existed that did not involve genetic enhancement of the conditions described. The line between enhancement and prevention, however, is not always as easily drawn. One thinks of the somewhat analogous situation of cosmetic surgery. The argument that such surgery can *enhance* self-esteem and improve performance in the competitive marketplace, etc., can also be made in the following way. It *prevents* loss of self-esteem which is a necessary condition for human flourishing, including flourishing in the marketplace. The difference between Anderson's example and this one is that his is of a physical disease. The therapy would result in a more normal functioning of the body. Cosmetic surgery is justified by certain cultural values that are used to judge oneself or to judge other persons. Anderson does, however, discuss growth hormones, which compare more closely to the example of cosmetic surgery. In that discussion, he leaves us with a question of its appropriateness: "Should a pubescent adolescent whose parents are both five feet tall be provided with a growth hormone on request?"⁹

These examples point to the broad question of what are the proper ends of medicine, a question raised sharply by Leon Kass's much cited article, *Regarding the End of Medicine and the Pursuit of Health*.¹⁰ The deep and perplexing questions are whether the purpose of medicine is to remedy impediments to more "normal" bodily functions or to enhance some normal functions? What constitutes the "normal?" Is the normal derived somehow from the "natural?" For example, if the use of the growth hormone in Anderson's example were withheld, would that be justified on the grounds that being relatively short is natural for that adolescent and therefore normal, making use of the hormone wrong? Anderson raises this issue when he asks what distinguishes a "serious disease" from a "minor disease from a cultural discomfort?"¹¹

Anderson also invokes the issue of fairness or justice in gaining access to genetic therapy and particularly to enhancement therapy. He inquires as to

7. See Anderson, *Considerations*, *supra* note 2.

8. Anderson, *Draw a Line*, *supra* note 2, at 688.

9. *Id.* at 690.

10. LEON KASS, TOWARD A MORE NATURAL SCIENCE 157 (1985).

11. Anderson, *Draw a Line*, *supra* note 2, at 687, 689; see also Anderson, *Malleability*, *supra* note 2, at 24.

how to determine who should receive a gene.¹² The more specific questions are those that have been raised about access to scarce medical resources. Should the persons granted access be those who can most benefit society? Those most in need medically to avoid significant suffering and premature death? Those who are able to pay? Or should it be by casting lots? It would be redundant to develop these last questions more; they are discussed widely in the literature.¹³

Anderson also asks how discrimination is to be avoided in gene therapy. Again the specific issues are those that arise from any genetic screening: Will persons be deprived of health insurance if they are not treated? Will certain persons be coerced into forms of enhancement therapy in a time of national crisis presumably for the sake of the public good?¹⁴

The value of individual autonomy is invoked against any arguments that would justify coercion even for the sake of a public good.¹⁵ It is clear that the larger vision of a "good" society is one that protects individual liberties. Whether there would ever be emergency circumstances that would override individual autonomy seems to be ruled out.

Another ethical argument that Anderson invokes is the "slippery-slope." He writes, "It would be difficult, if not impossible, to determine where to draw a line once enhancement engineering had begun. Therefore, gene transfer should be used only for treatment of serious disease and not for putative improvements."¹⁶ In a sense we are already on this slippery slope since the capability exists to engage in genetic engineering. As on other such slopes, a site is located beyond which we ought not go. Some things ought not to be done even though they can be done. Anderson's line between serious disease and "putative improvements" was commented on above; what is the basis for drawing the distinction he has made?

Third, Anderson suggests the *importance of public approval* of possible germ-line interventions.¹⁷ He indicates that public approval will evolve over time. Thus, part of the medical-ethical strategy is to educate the public to get its approval for therapies that are medically and ethically possible and legitimate. Presumably a corollary of this is to gain support for discussion of problematic possibilities and perhaps for drawing a firm line against some of

12. Anderson, *Draw a Line*, *supra* note 2, at 688.

13. See, e.g., DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* (1987) (discussing what the appropriate level of individual health care should be given the existing lack of health care access and escalating costs).

14. Anderson, *Draw a Line*, *supra* note 2, at 688.

15. *Id.*

16. Anderson, *Malleability*, *supra* note 2, at 24.

17. Anderson, *Considerations*, *supra* note 2, at 286.

them. There is a broadening context of discussion; experimental germ-line therapies are not matters to be agreed upon only between physicians and their patients or appropriate surrogates, as decisions about surrogate motherhood are.

The important practical question of how medically and ethically informed public discussion is to take place is not broached in Anderson's articles. Persons who have attracted wide public attention, such as Nicholas Wade and Jeremy Rifkin, are cited for their alarms about the potential abuse of power that might slide down the slope to eugenics. Anderson is somewhat sympathetic to them as he asks are they really that far off the mark? I raise the practical question because it is easier for prophetic alarmists to gain public attention than it is for persons who are prudently complex about both the medical and moral dimensions. Genetic therapy is just one example of a larger issue in our society: How is an adequately informed public opinion to be developed on critical and controversial issues? Do we have institutions and processes in place for this to occur?

One of Anderson's discussions of germ-line therapy contains an intriguing claim. "The gene pool is a joint possession of all members of society," which would be affected by outcomes of germ-line therapy.¹⁸ This demonstrates his concern for public discussion and approval. Anderson does not specifically discuss the probabilities of long range beneficial or deleterious outcomes in the gene pool. Possession is a term that suggests a legal structure invoking laws of property and requiring a local governmental authority to determine its lawful use. The social, legal, and ethical ramifications of this concept, if taken seriously, are great. Who is the guardian of the gene pool? By what authority? What powers does the guardian have? How are they to be exercised?

Fourth, and finally, in Anderson's writings, there are appeals to *profound background conditions*, more belief conditions than scientific knowledge conditions. They are introduced by some of Anderson's questions. What constitutes human dignity? What is significant suffering? What is normal? His 1989 article,¹⁹ in particular, cites a breadth of literature by ecclesial authors and groups, moral theologians and ethicists, and others that address these perplexing questions. As noted earlier, Anderson does not seek to resolve them, but is clearly conscious of them.

WHAT IS DISTINCTIVELY HUMAN?

The remainder of this paper will be no more successful in resolving the

18. *Id.*

19. See Anderson, *Draw a Line*, *supra* note 2.

questions raised than Anderson has been, but serves to widen the discussion. At this point, I move from particular attention away from Anderson's writings to broader issues.

We necessarily find ourselves in a morass. We are in an area of long and continuing discussion and debate. Four principal and related questions arise following a review of the literature. They are: 1) How do we adequately describe and explain what is distinctively human?; 2) What do we value about the human?; 3) What ought we to value about the human?; and 4) How are our descriptions and explanations on the one hand related to our valuations on the other? These questions are probably as old as critical human self-consciousness. While the divisions of judgment on them are not overcome, there may be some minimal consensus which makes an inviolable standard of value in Western Culture.

Only three authors are quoted—from the many that could be used—to show the pervasiveness of the quest for answers to these questions. Reinhold Niebuhr opens the first volume of his 1939 Gifford Lectures as follows: "Man has always been his own most vexing problem. How shall he think of himself?"²⁰ Margaret Mead wrote, " 'What must we do to be human' is a question as old as humanity itself."²¹ Melvin Konner opens *The Tangled Wing* with, "Why are we what we are, why do we do what we do, why do we feel what we feel; these questions have been on the minds of philosophers and theologians, medical men and medicine men, actors, diplomats, poets and, of course, scientists, beginning with the first glimmer of human thought itself."²² Carl N. Degler analyzes the history from the early impact of Darwinism to the pre-eminence of culture as the best explanation of human nature to the resurgence of biological considerations.²³ James Luther Adams wrote a penetrating essay in 1942, which focused on liberalism as a tradition.²⁴ Citations to discussions, of course, could continue indefinitely. The point here is to affirm that the background beliefs about what might support, if not directly warrant, the moral legitimacy or proscription of certain genetic therapies in humans continue to be much debated.

Returning to the questions asked above, "How do we adequately describe and explain what is distinctively human?" At one level, there is a biological answer, namely that humans have a distinctive chromosome. This is a necessary condition for the distinctively human being. Noting its existence,

20. REINHOLD NIEBUHR, *THE NATURE AND DESTINY OF MAN* 1 (1941).

21. CARL N. DEGLER, *IN SEARCH OF HUMAN NATURE* 3 (1991).

22. MELVIN KONNER, *THE TANGLED WING* xi (1982).

23. See DEGLER, *supra* note 21.

24. JAMES LUTHER ADAMS, *The Changing Reputation of Human Nature, in VOLUNTARY ASSOCIATIONS* 14 (1986).

however, is not a sufficient description or explanation of our humanness. Our biological distinctiveness is both small and decisive. Without detailing the arguments by various authors, focusing on the biological impresses many writers in ethology and sociobiology with the continuity between the human and other living creatures.

This orientation relies on the findings of science, and has been used to interpret human activity in more deterministic ways. In response to such interpretations, some writers, *e.g.*, Barry Schwartz, pose a "battle" for human nature between those who argue for the hegemony of the language of science and the hegemony of the language of morality.²⁵ The outcome of the battle will affect the human sense of moral accountability. Other writers who are disposed to biologically explain as much about the human being as possible, like Konner, also want to include the human capacity for awe and wonder which inhibits a reductionism and provides a basis for adhering to what our culture reveres as humane values. Still others, Mary Midgely for example, seek to avoid the language of battle and observe complementary relation between what we are biologically, culturally, and morally.²⁶

Other authors from various disciplines stress the distinctiveness of the human in radically different ways. Reinhold Niebuhr uses the language of "spirit." Spirit is embodied but points to our capacities for freedom and self-determination. John Calvin says that it is "worship" that distinguishes humans from what he calls, in typically sixteenth century western fashion, "brutes."²⁷ Sir John Eccles interprets the relation between brain and mind in such a way that there can be an individual unique soul, and this belief guards against tendencies to develop oppressive slave states.²⁸ Rabbi Abraham Heschel sees the capacity to be responsive to ourselves, to others, and to God as the proper description of the human.²⁹

Moves have been made to some middle ground. Degler's historical account of American social thought sees the work of anthropologist Franz Boas and his students as the apex of interpretations which minimized, for a period of time, the importance of biology and stressed the importance of human capacities to create culture. Thus, humans were judged to be determined more by culture than biology. Degler's analysis shows that in more recent decades the connection or relationship between the biological and the

25. BARRY SCHWARTZ, *THE BATTLE FOR HUMAN NATURE: SCIENCE, MORALITY AND MODERN LIFE* 17-18 (1986).

26. See MARY MIDGLEY, *HEART AND MIND* (1981); MARY MIDGLEY, *BEAST AND MAN: THE ROOTS OF HUMAN NATURE* (1978).

27. JOHN CALVIN, *THE INSTITUTES OF THE CHRISTIAN RELIGION* 47 (1960).

28. JOHN C. ECCLES, *THE HUMAN MYSTERY* 144, 236-37 (1979).

29. ABRAHAM J. HESCHEL, *WHO IS MAN?* 16 (1965).

cultural is a focus of attention.³⁰ Theologian Edward Farley is not wholly untypical of his discipline when he seeks to take account of the biological in developing his theological interpretation of the human.³¹

Is anything at stake in these arguments which affect, in at least some indirect way, choices about genetic therapy? The answer is not clear, but scenarios can be proposed which begin at opposite points of the discussion. First, if we begin with views that tend toward biological determination, if not reductionism, research could focus on not only the biological conditions which impede health but also those which might enhance the biological distinctiveness—with some presumed benefits in mind. Dr. Anderson raised one example in his articles, the improvement of memory. Should it become possible to inject something which would improve memory, would we consider this beneficial enough to warrant experimentation and therapy? Emphasis on biological determinants of distinctively human activities and capacities has, and could in the future, support both radical eugenics and enhancement therapies. These would be somewhat analogous to current use of performance enhancing drugs. The main issue is what is naturally normal and does this provide a moral guide?

Second, if we begin with those views that tend to stress freedom or voluntarism, spirit, responsiveness and responsibility, and creativity, one affirms the present requirement of informed consent to an invasive procedure. But in and of themselves, these qualities I shall call “spirit” could be more than a basis for limiting interventions. Indeed, freedom and creativity are exercised in the progressive development of biological knowledge and the development of therapies. Human beings, being only slightly less than the angels—according to the much quoted eighth Psalm—have godlike capacities to master and dominate nature. Alternatively, as Lynn White noted, they can exercise dominion over nature according to a Genesis creation myth.³² White’s theory, without consideration of other factors, *could* support aggressive intervention for the sake of human control and domination. To be human is to maximize our creative capacities to order nature.

Several knotty issues arise in the literature on the nature of the human being. From a more biologically deterministic view, how is the “human spirit” *explained*—the sense of wonder, for example, that Melvin Konner strongly affirms? From the more “spiritual” view, how does one take into

30. See DEGLER, *supra* note 21.

31. EDWARD FARLEY, GOOD AND EVIL: INTERPRETING A HUMAN CONDITION 76-96 (1990).

32. Lynn White, *The Historical Roots of our Ecological Crisis*, 155 SCIENCE 1203, 1203-07 (1967).

account the evidence of genetic and other biological research with their increasing power to explain humans?

This is the point to comment on the biblical distinction that is invoked by theologians to answer the question. The distinctively human being is both explained and described by the assertion that human beings are created in the image of God. The invocation of this biblical statement is less helpful than one desires. There is an inherent circularity in the statement. With varying interpretations of God come varying ideas about the image of God that is in the human being. And, with varying interpretations of the distinctiveness of the human ascribed to both God and the human being in the image of God, come varying interpretations of God. Historically, different content has been ascribed to both God and the human being to reduce the formality of the statement. For example, there are arguments for rationality as the image, as there are for historicity or the capacities to be creative. Recently the Canadian theologian, Douglas Hall argued for interrelatedness as the image.³³ Sallie McFague suggests a variety of models of God each of which would have a corollary for the image of God in the human, and for the kinds of practices that are appropriate in an ecological and nuclear age. She discusses two classic models, the monarchical and the idea of the world as God's body, and then proposes consideration of God as mother, as love, and as friend.³⁴

The moral function of the idea of humans created in the image of God, for those who invoke it, seems to be that it is a regulative idea of respect for the human and of fundamental equality of all humans. Its function is comparable to that of respect for persons in Kant's moral philosophy and other principles in other writings. It is not a principle, the content of which is positive and full of defined "goods" or "values," but one that has to be raised as a limit or even a question. Do certain therapeutic interventions violate the principle of respect for humans? Is therapy available or accessible to all who need it? This does not of itself, because of its formality, provide a positive basis for precise determination of right or wrong interventions or who should have access to therapies under specific conditions. But it is one answer to our first question in this series of four; it is an explanation and description of the distinctively human being.

What do we value about the human being? This is an empirical question. One finds answers to it in various studies as well as in literature and art. An inventory of answers would require a list pages long, showing cultural variations, class variations, and variations under different life circumstances.

33. DOUGLAS J. HALL, *IMAGING GOD: DOMINION AS STEWARDSHIP* 88-112 (1986).

34. See generally SALLIE MCFAGUE, *MODELS OF GOD* (1987).

General answers have been given. We value life itself, we value happiness or well-being, we value our eternal destinies. What humans value about themselves is subject to moral scrutiny and judgment both by themselves and by others. Thus, for example, there are those who believe that a technological imperative exists in modern medical science that backs every effort to prolong the length of physical life. This seems to make extension of life an end in itself and not take sufficient account of the qualities of the extended life. The criticism is based upon various qualities that can be valued more highly than life itself. Many examples could be cited for criticisms of what persons or communities do value about life and of what we ought to value about human life. In every case, it is clear that the major question is not solved by opinion polls about what we value.

Still, it can be argued that individuals or communities have the freedom and right to value what they choose to value. If this is so, then genetic therapies could be directed by whatever can be done to fulfill a desired outcome for persons or communities. If persons desire, and thus value, greater height than predicted on the basis of the height of their parents, growth hormones would be licit. If memory enhancement is valued, then access to therapies that enhance memory would likewise be licit. The "is" of whatever is valued would determine the "ought" of what should be developed and made accessible to persons.

It is clear that Dr. Anderson and others are not prepared at present to make the fact that individuals value some possible outcome of genetic therapy sufficient ground for their receiving that outcome. Some "ought" is functioning to limit and direct choices about therapy, if not research.

What ought we to value about the human? This is, of course, the most crucial question, and genetic therapy is only one locus among hundreds in which the question is relevant. A legitimate case can be made that we ought to value many things about human life.

The history of earlier eugenics proposals is instructive at this point. Critics often cite geneticist S. J. Muller, who proposed to bank the semen of men who were, in his judgment superior, and employ artificial insemination. He chose names of men through history who he thought no intelligent and morally sensitive woman would refuse to father their children. Muller listed Lenin in one version. Later Lenin was dropped and Einstein, Pasteur, Descartes, da Vinci, and Lincoln were listed.³⁵ During the flurry of literature on cloning a human being, critics asked which traits of the human ought to be replicated in identical ways and in significant number by cloning.

35. See PAUL RAMSEY, *FABRICATED MAN: THE ETHICS OF GENETIC CONTROL* 39-62 (1979).

One of the first questions to this is always, "Who has the authority and the power to determine what we ought to value about human life?" The specter of authoritarian governments determining which persons ought to be eliminated from the human race because of certain "deficiencies," or because of ethnic affiliations should haunt every reflection about answers to this question. More subtle forms of external determination have been cited in both earlier and current stages of the uses of therapy that require scarce medical resources. One thinks of the often told tale of the Seattle Dialysis Program during the early stages of end-stage renal therapy in which a committee of citizens attempted to use various social and other criteria of worthiness.³⁶ The availability of economic resources for medical care continues to mark a line between those who have access to therapy and those who do not, between those whose beliefs about what ought to be valued about life can be met and those whose beliefs cannot be met.

This question asks whether our society ought to determine policies on the basis of "thick" theories of human good which define the desirable ends in view on the basis of some authority, or a "thin" theory of good which tolerates a variety of conceptions of human good and works out procedures that honor individual liberty and fairness so that access to genetic therapies is not determined by the authority of the medical profession, insurance companies, or other centers of power. In the ideal worlds of philosophers and theologians, principles can be worked out and procedures proposed to avoid some unfairness and to honor self-determination. In the world of limited resources, which is always the case in experimental therapies, decisions have to be made about what values of the human being ought to influence, if not determine, who has access to therapy.

These decisions are made on the basis of medical criteria within the context of the state of knowledge and the nature of the diseases at hand. Dr. Anderson, for example, invokes severity of disease as a criterion. In life threatening circumstances, interventions are judged to be morally licit when, under other circumstances, they would not. Attempts to analyze what factors go into these priority judgments have been made elsewhere and will not be elaborated on.³⁷

Karl Barth wrote, "Life is no second God, and therefore the respect due to it cannot rival the reverence owed to God."³⁸ This makes the theological point that whatever we value and ought to value about life is at least relative to the respect owed to the creator, sustainer, and orderer of our life. The

36. See RENEE C. FOX & JUDITH P. SWAZEY, *THE COURAGE TO FAIL* 226-65 (rev. ed. 1978).

37. JAMES M. GUSTAFSON, *ETHICS FROM A THEOCENTRIC PERSPECTIVE* 254-77 (1984).

38. KARL BARTH, *CHURCH DOGMATICS* 342 (1961).

practical inference is toward what we ought not to value about human life; the sheer perpetuation of it for its own sake as a form of idolatry. This would be an effort to transcend human mortality, and to usurp, in Barth's language, the prerogatives of God.

While there without doubt have been, and continue to be, medical interventions whose purpose is simple prolongation of biological functions, nothing in Dr. Anderson's justifications of genetic therapy appeal to this end. There have been discussions about research into the genetics of the aging process and possible justifications for interventions once those genetic factors are discovered. Leon Kass has written a profound critique of such proposals: "Once we acknowledge and accept our finitude, we can concern ourselves with living well, and care first and most for the *well-being* of our souls, and not so much for their mere existence."³⁹ Paul Ramsey made a similar point in one of the better one-liners he bequeathed us: "Men ought not to play God before they learn to be men, and after they have learned to be men they will not play God."⁴⁰

These views, derived not only from proposals to intervene in the aging process but also from other proposals for radical genetic therapies, have a prophetic function. They look below, beneath, or beyond particular proposed therapies and present us with a warning to be heeded. But the prophetic warning does not resolve the clinical issues; "well-being of our soul" does not in itself specify what ought to be valued about living well, though Kass has more to say about that than can be cited here.

THE MORAL STATUS OF THE NATURAL HUMAN LIFE

The most difficult issue, the one that puzzles without a firm resolution, is this: What is to be judged as *natural* in human life, and how is what we judge to be valued about life related to the natural? This is to ask question four: How are descriptions and explanations of the human related to valuations of it? In one sense, every genetic therapy is justified on the ground that it either relieves an impediment to proper natural functioning, as in preventive somatic cell therapy and possibly in some future germ-line therapies, or improves some aspect of the natural that is especially valued in enhancement therapy and radical eugenics. Put a bit differently, what is normal in our biological processes, and what is judged to be abnormal and thus worthy of correction by preventive genetic therapy? What is judged to be normal such that it is worthy of such higher valuation that it warrants enhancement or radical eugenics?

39. KASS, TOWARDS A MORE NATURAL SCIENCE 314 (1985).

40. RAMSEY, *supra* note 35, at 138.

Philosophically, this raises the much discussed question of the relation of the "is" to the "ought," but in the abstract any resolution of that does not necessarily resolve particular clinical choices. Some judgment of what "is"—e.g. a medical condition—is seen as a threat to certain goods or values of human well-being, implying an "ought". Or what "is"—e.g. a decent memory—might be judged to be of such value that it ought to be enhanced. Some reference to medical conditions is critical to what *ought not* to be done as well as what ought to be done. In the *ought not*, as well as the *ought*, in some sense (and in the *some* lies the puzzle), the biologically natural is referred to as normal. That normal is at least one of the bases on which a judgment about the moral propriety of therapy is made. Those bases clearly shift with the development of knowledge about genetics as they have with the development of other aspects of biological research. New genetic knowledge becomes the condition for enlarging therapeutic interventions, for different moves from what is known more accurately as research develops to what ought or ought not to be done. But the ought, or ought not, is not simply logically deductible from that knowledge.

Only persons with certain religious beliefs could claim that medical therapies are always illegitimate and that "nature" should be permitted to take its course under all circumstances, even if this leads to readily avoidable suffering or premature death. At the other extreme, death denying (a preferred term for what usually are called life prolonging) therapies are used on an individual moral judgment basis. Most of us find our beliefs somewhere between the extremes.⁴¹

When one argues that certain interventions ought never to be undertaken, one does well to remember some history in which interventions were said to be wrong on the basis of "do no harm," or other principles. "Do no harm" can be interpreted in a restrictive way, inhibiting developments in the relief of suffering and avoidance of premature death. The functioning limit of using therapies only for preventive purposes assumes that the procedure will eliminate or deter a threat to what is judged a normal functioning of the organism. One is reminded of Thomas Aquinas, who believed that surgery was justified when it removed a threat to the well-being of the whole body—society. What is the contrasting injunction to "do no harm?" Is it "benefit to the extent possible?" Practically, do no harm has been a restriction of means in the process of making benefits possible. The benefits seem to have come from the restoration of more "normal" functioning of the body until recent decades.

41. Richard Landau & James M. Gustafson, *Death is not the Enemy*, 252 JAMA 2458 (1984).

My impression is that in justifications of experimental or routine therapies, the biologically normal functions are one basis for the medical-moral choice. A statistical norm is used or implied. The abnormal condition is that which threatens the normal, and its abnormality warrants intervention given adequate knowledge and other conditions. The normal alters with various conditions; what is normal for a young person is not normal during old age. The normal, then, fluctuates and deviations from it have to be described and judged for their severity. But in experimental genetic and other therapies, this is not sufficient to justify an intervention.

Dr. Anderson's and others' restraints on enhancement therapies and radical eugenics are based on a conviction that the naturally normal in a biological sense is the basis for a moral norm. They can find no compelling moral justification for improving the naturally normal in most or all possible cases.

For the theologian, this raises a question which also can be raised from other starting points, namely, what is the relation of the naturally normal to what one might want to claim about the divine ordering of life—biologically and humanly? Is the theologian justified in setting Anderson's biologically normal in the larger context of meaning and value that theology attempts to speak about? There is no consensus about this in historical or contemporary western theology. Other efforts to deal with this issue are published elsewhere and are too complex to develop here.⁴² God, the ultimate power, is ordering life in the world through the patterns and processes of interdependence. These patterns and processes are *one basis* for ethics, but not a sufficient one. From one theological perspective, it can be concluded that a careful assessment of Dr. Anderson's articles on ethics are conscientious efforts to discern not only what genetic therapies would be morally justified but also which would be religiously and theologically supported.

If there is reason for some confidence that conditions of moral responsibility are being met by Anderson and others, what are they, and how can they be sustained and enhanced? Previously, developments over the past twenty years that enhance moral responsibility have been mentioned. Anderson's concern for the public implicitly acknowledges a political dimension that must be taken into account. Success in bringing morality to bear on genetic and other experimental therapies has come from the development of regulations that have to be met and from the conscientiousness of investigators and an informed public. In effect, moral interest groups have gained access to persons of authority to set these regulations. Regulations were established because the moral trustworthiness of investigators has been challenged. Surely what is needed are more of what I have called "communities of moral

42. See GUSTAFSON, *supra* note 37.

discourse” in which the scientific, medical, ethical, and political issues are engaged by informed and intelligent persons who represent different interests and different perspectives on the nature of humanness and human well-being. Churches, universities, and other institutions can provide some of the specialization and diversity needed to include the many considerations that should be addressed. Media presentations often focus on the more dramatic and esoteric possibilities; they use what Hans Jonas has called the “heuristics of fear” to alert persons to potential and actual dangers.⁴³ There is no substitute, however, for the hard work of cross-disciplinary discourses which involves sufficient knowledge of the information, concepts, and ways of thinking represented by specialties and interests.⁴⁴

43. See HANS JONAS, *THE IMPERATIVE OF RESPONSIBILITY: IN SEARCH OF AN ETHICS FOR THE TECHNOLOGICAL AGE* (1984).

44. Oral and written exchanges with Professor Donald Rutherford, Department of Philosophy, Emory University. While these exchanges were focused on a different project pertaining to Dr. Anderson's work, they stimulated the renewal of my attention to the ethics of genetic therapy. I gratefully acknowledge the importance of these interactions, which may perhaps result in a more specific analysis than is rendered here.