3-1994

From Clinic to Congregation: Religious Communities and Genetic Medicine

M. Therese Lysaught
Loyola University Chicago, mlysaught@luc.edu

Recommended Citation

This work is licensed under a Creative Commons Attribution-Noncommercial-No Derivative Works 3.0 License.
Although many factors drive genetic research, a fundamental impetus is one that undergirds medicine itself—the moral duty, obligation, conviction that we are to relieve human suffering, to cure human illness, when we have the capability and the moral freedom to do so. Fueled by this conviction and the massive federal funding of the Human Genome Project, the database of information about genetics and technologies tailored to this data grow at a phenomenal rate. Almost daily, newspapers announce the discovery or near-discovery of another new gene.

Essential to this impetus is a second conviction, one less familiar to conventional medicine—a belief that locates disease in an individual’s genetic structure. Thus, as presidential task forces and policy analysts currently attempt to reform the external structure of health care delivery, a quieter, subtler reformation—or better, transformation—is already occurring within medicine: a metamorphosis to genetic medicine. A genetic approach to medicine not only redefines what constitutes “disease” and “health.” When translated into the clinical setting, it shifts the traditional province of medicine from a crisis-management acute care model, which attends to problems as they become manifest, to a model of “predict and manage,” which anticipates and seeks to forestall disease and illness through lifestyle and environmental management or genetic intervention.2

As this metamorphosis continues, individuals will more frequently find themselves immersed in a health care system that increasingly speaks the language of genetics. Many of these individuals will likely be some of the 145 million individuals who worship in one of the 358,000 religious congregations in the U.S.3 As such, they will go from the offices of physicians and genetic counselors

The human genome project is an attempt to identify all the genes on the human chromosomes that determine the biological makeup of every individual. Armed with such knowledge, argues M. Therese Lysaught, doctors will face intense pressure to practice medicine in a way that differs radically from practice at present. Rather than responding to disease, they will attempt to eliminate the biological conditions that create disease in the first place. The church as a community of distinctive moral discourse needs to become familiar with the genome project and its consequences for medicine, so as to be able to make informed and appropriate decisions. Ms. Lysaught is a research associate at the Park Ridge Center in Chicago.
f to the offices of clergy and pastors, seeking guidance on how to interpret the information they have received, how to locate the information in a context of belief that will give it meaning, how to envision and weigh the implications of various courses of action. They will want to know: "If I am at a high risk, should I have my fetus genetically screened?" "I have been told I possess the gene for X—what does that mean?" "Should I avoid having children?" "Will gene therapy change my daughter's identity?"

To begin the process of giving meaning to information about genetics, congregants and pastors might turn to theologians or chaplains who participate in the dialogue between religion and genetics. However, in what little has been written to date, recent advice of those who represent religion in these discussions indicates a disheartening trend, evident in theoretical positions:

Advances in genetics occasioned by the Human Genome Project call for Protestant and Roman Catholic theologians to re-examine the adequacy of traditional interpretations of creation, human nature, moral choices, and the relation of humanity to nature. Posing these questions and suggesting that answers might be found in the notion of ongoing creativity could become significant as religious leaders wake up to what is going on in research... The fear of the unknown future seems to be fueled by a desire to locate something unchanging within the material world, something that connects us with the eternal and unchanging God... Should this religious disposition prevail, the present generation will be accused of "playing God," and theological arguments will be mustered to call for a halt to further genome research. If this happens our churches might find themselves in the embarrassing position of advocating ignorance over knowledge, of supporting the status quo in preference to transformation.

1This paper originated out of two lectures, one to a meeting of the Christian Action Commission of the Reformed Church in America held at Hope College in Holland, Mich., and the other to members of Holy Trinity Lutheran Church, Glenview, Ill. I am grateful to my colleagues Dan Dugan and Ron Hamel for their helpful editorial comments.


4Religious voices have been active in ethical discussions since the beginning of the genetic era. For brief overview of this history see J. Robert Nelson, "The Role of Religions in the Analysis of the Ethical Issues of Human Gene Therapy," Human Gene Therapy 1 (1990): 43-48.


6Ted F. Peters and Robert J. Russell, "The Human Genome Project: What Questions Does It Raise for Theology and Ethics?" Midwest Medical Ethics (Summer 1992): 12-17. Emphasis mine. It is interesting, or more precisely, puzzling, to me that these fearful, backward religionists who prefer ignorance to knowledge, are accused of "supporting the status quo." One could marshall significant evidence to illustrate that the current status quo is defined by the technological imperative: if it can be done, it must be done. The current status quo is one that allows no limits to technological innovation—or "transformation" in Peters'
The same trend is also evident in practical positions:

Religious groups should advocate adequate access to reliable genetic information and counseling services, and appropriate training for genetic counselors. Clergy are in a unique position to link the issues of genetics to religious or spiritual teachings and practices. This is part of their job. But clergy, no less than physicians and other hospital personnel, must be careful not to dictate choices. Biases regarding what constitutes quality of life, especially, have no place. Clergy should act as educators, not enforcers of rules. Autonomy and free will are closely related.

Implicit—or not so implicit—in these statements is a shared conviction: religion is to be the handmaid of science. Religious groups and religious professionals are called to use their social influence to advance the cause of genetics. It is time, we are told, for religion to catch up, to “wake up,” to scientific advances, progress, truth and discoveries about the human condition. Religion—authoritarian, unreasoning, absolutist, and fear-driven—is portrayed as intellectually, epistemologically and ethically inferior to science, that value-neutral promoter of creativity, rational inquiry, and human progress. The “truths” discovered by science demand revision in religious beliefs.

Pastors who heed this one-sided counsel fail in their calling and fail their parishioners. Clearly, pastors and theologians should not simply reject genetics out of fear and ignorance; equally they ought not act as cheerleaders to advance the cause of genetics qua science and progress. Rather, clergy and theologians are called to engage their communities in processes of moral reflection and action, forging with congregants well-reasoned, theologically and scientifically informed frameworks for evaluating questions, challenges, and resources raised by genetics. These frameworks will, in different instances, lead congregants to abjure some particular genetic endeavors, to tread tentatively in the face of others, and to welcome still others. Moreover, when these frameworks offer viable alternatives to practices logically indicated by genetic technology, they words. It takes little moral courage to give science a blanket endorsement to keep on doing what it has been doing and what it wants to do. Aristotle defined courage as being afraid of the right thing in the right situation; it takes one with moral courage, who has sufficient creativity to envision possible negative outcomes, to challenge the status quo and muster good theological arguments which might weigh against a particular genetic endeavor.


2. Laurel Arthur Burton, Suzanne B. Yellen, and Ellen Elpem, “Making Use of the Patient Self-Determination Act,” The Christian Century 109:20 (June 17-24, 1992): 617. This passage comes out of a reflection on advance directives, but the general position is reflected in literature on genetics and, given the authors’ premises, can be extrapolated to genetics. While my position also promotes clergy as “educators,” the literature tends to suggest that clergy be “non-directive.” However, as leaders, clergy are called to be directive—not biased, but directive. It is part of their job to marshal the best arguments and social/communal resources in support of theologically sound positions. It is also part of their job to practice true forgiveness, which is not equivalent with tolerance.
will do so because they emerge out of and are translated into moral action, namely, liturgical and social practices which embody the framing convictions and create in the world ways of living with genetic differences and uncertainties. By modelling such alternatives, religious communities may well help society to "wake up" to the ideological and culturally-laden implications of certain genetic technologies; like religion, science too can be "fundamentalist."

But first, clergy need to attend to the problems faced by their parishioners as they move from clinic to congregation. In order to think and live faithfully in the face of genetic information, parishioners need: (1) a renewed understanding and experience of the religious community as a place of moral discourse and moral formation; (2) basic and up-to-date information about genetics, its history, its social context and function, its limits and its possibilities; and (3) ongoing dialogue on how new choices created and imposed by genetics and medicine bear on issues of major concern to the Christian faith. In the following, I will comment, albeit too briefly, on each of these.

I. Christian Communities as Places of Moral Discourse

Substantive moral discourse—which is by definition "public"—has become increasingly elusive in our culture.\(^9\) The problem, it is claimed, is that the warrants used by most people for moral evaluation and decision-making—our particular identities and commitments, especially cultural beliefs and religious convictions—are personal, private, and incommensurate. So personal are they, in fact, that to evoke or invoke them often seems a novelty or a breach of the etiquette of public exchange. Worse, however, it is claimed that they are destructive of public tranquility and cohesion by forestalling the possibility of communication, understanding, and consensus. Public life and its moral discourse is therefore rendered either as unfettered pluralism celebrated for its own sake or a thin, grey universalism which renders all difference invisible.

Over against these extremes stands the alternative of Christian communities—waning, it is true, but still viable. Members of Christian communities—although far from uniform—claim and are claimed by commonalities: a common activity of worship, a common language of faith, a common story of the Gospel, a common text of Scripture, common practices such as baptism, forgiveness, and prayer, common beliefs about the character of God and the world, the common task of discipleship. These commonalities resist the fragmentation and

---

\(^9\) Most are familiar with Alasdair MacIntyre's description of the incoherent state of contemporary moral discourse and his diagnosis of the problem in the severing of moral frameworks from their communal, anthropological, and traditional correlates (After Virtue (Notre Dame, Ind.: University of Notre Dame, 1981)). H. Tristram Engelhardt has proposed a moral framework coherent with specific anthropological and sociological structures of our culture, but rather than rectifying the chaos, it renders normative the impossibility of reasoned public moral discourse informed by particular commitments (The Foundations of Bioethics (New York: Oxford, 1986)).
idiosyncracy of contemporary culture. They create a “public” forum by providing shared components for building a shared identity, a common moral framework. Such a framework supplies the context within which differences in individual experiences, identities, and understandings can be meaningfully discussed.

Moreover, these commonalities provide not only community but content, particular visions of human flourishing that shape contexts for interpretation. Members of Christian communities claim that embedded in their traditions and embodied in their practices are truths that provide premises for reasonable arguments: that God exists; that God’s character is of a certain sort; that God intends certain ends for human beings and relates to human beings in certain ways. These are convictions which guide people’s actions—even if tacitly—convictions by which people orient their lives, “in their worship, and in their living and their dying and their suffering and their caring for the suffering.”

While the nature of contemporary public philosophy renders it difficult to identify operative or tacit religious convictions in public moral reflection or integrate them where possibly indicated, Christian communities can provide models of what this integration might look like, as Allen Verhey has noted:

Although this is an ideal which few congregations meet, it is a challenge to which congregations are called.

But congregations provide not only the communal conditions of possibility and content for moral discourse and action; they also supply models of it. Many try to reduce religion to “themes” or “beliefs” or “principles” which can be applied to a situation apart from the agents involved or a communal worshipping context. But religious beliefs are neither self-evident nor self-interpreting. An ability to see and understand religious dimensions of life and events is forged over lifetimes and through communal and embodied practices. In this process, we learn from others. From the stories of Scripture and experiences of others, we learn how to see what God’s grace looks like in events. From others in the tradition and in the community, we learn how—and how not—to understand the stories of Scripture and to correlate them with seemingly novel situations. From the successful and less-successful attempts of others to live faithfully, we learn what discipleship “looks like,” not in 50 c.e. Palestine but in navigating contemporary culture. From others we learn how to forgive ourselves and others


for inevitable moral failure. Others demonstrate how the rituals and practices of Christian life can sustain us in and through times of confusion.

None of this is easy, of course, nor will it always be successful; Christian communities are often known more for their error and politics than for being well-informed and well-intentioned. Like the moral life generally, moral discourse within Christian communities will not be tidy, will not supply easy, clear-cut answers. Moral discourse within Christian communities will most often focus not only on the “what to do” but also on questions of “why ought I do X?” or “how do I go on in the face of Y?” These questions now arise out of individuals’ experiences of genetic medicine. In order adequately to deliberate on the “what,” “why,” and “how” of genetics, clergy and congregants need to understand the basics of genetics, the technologies it generates, and the social practices that are evolving from genetic capabilities.

II. Genetics and “Genetic Medicine”

In order to give a sense of the complexity of genetics, of the truly technically fascinating capabilities of genetic science, of the types of jargon and concepts individuals will encounter, of the processes that might seem, on first glance, to be morally dubious but that may in fact be functioning as moral red herrings (such as the ominous sounding “murine retroviral vectors”), I would next like to outline some of the fundamental concepts of genetics, technologies they have generated, and some of the issues raised. While this portrayal will be admittedly incomplete, in it I will try to display what currently serve as the three major components of genetic medicine: genetic testing, genetic therapy, and genetically-engineered pharmaceuticals.12

Like any scientific field, genetics has developed its own arcane language. Long before one can begin to interpret a bit of genetic information, one must understand the words and the grammar.13 Although their meaning may be far

---

12In this paper, I am attempting to focus on the clinical manifestations of genetics—that which congregants will encounter. Consequently, I will not directly engage the issue that has probably received more attention than any other—the issue of the creation of new life forms. Initial antagonists in the debate were most heated about the ability of recombinant DNA techniques and transgenic experiments to create new species or to alter the “species essence” of humanity. Some were concerned about the impact of these activities on the ecological balance; these and questions of biodiversity remain central. These issues resulted in much theological reflection on nature and creation.

13The importance of understanding language for adequate interpretation is revealed by a recent Harris/March of Dimes survey. Respondents were asked if they approved or disapproved of gene therapy. 89% of those polled said they approved of gene therapy while 60% of the same pool confessed that they had heard almost nothing about the technique (New York Times, 9-29-92, B6). Not only must one understand this language, but one must be vigilant as well, insofar as the terms and phrases used often do a good bit of marketing. For example, the phrase therapeutic abortion adds a new procedure to the traditional armamentarium of therapy—i.e., ending a life. Likewise, both disease cure and
from clear, the fundamental terms of genetics are by now familiar: chromosomes, DNA, genes. The nucleus of each cell in the human body (except the reproductive cells) contains 46 chromosomes—23 pairs. One chromosome in each pair comes from each of an individual’s parents. From cell to cell within a particular person’s body, these chromosomes are essentially the same; slight variations can be introduced if mutations occur during the replication of a cell.

Chromosomes are composed of a substance called DNA—deoxyribo nucleic acid—which is, in turn, composed of four molecules called nucleotides (adenosine, thymine, cytosine, and guanine), represented with the letters A-T-C-G. Thus, chromosomes are essentially very, very long chains of molecules of A, T, C, and G. The order in which these molecules appears within a given segment of DNA—...ATGCGCTAATGCGCTAATCGTACGCGCGATGC...—is often referred to as a “code,” for through an intricate process of translation of this sequence, DNA directs the production of every protein, enzyme, and cell in the human body. A DNA segment that contains the sequence or code for an entire molecule or product is called a “gene.” There are an estimated 50,000 to 100,000 genes in every human cell, containing up to 6 billion nucleotides. Thus, a single chromosome could conceivably contain an average of 2,000 genes, while a single gene could conceivably contain an average of 60,000 nucleotides that must be sequenced in a particular order for the gene to function correctly, that is, to produce the proper protein.¹⁴

Aberrations in genetic structure are thought to cause approximately 3,000-5,000 diseases or physical conditions, including: enzyme deficiencies, familial hypercholesterolemia, Lesch-Nyhan syndrome, phenylketonuria, Gaucher disease, Hunter syndromes, sickle cell anemia, thalessemias, hormone production defects (such as absence of growth hormone), Tay-Sachs, Cystic Fibrosis, Huntington Disease. In conditions such as these, some alteration in the nucleotide sequence or in the location of the gene causes the body to produce either excessive amounts of some body proteins, dysfunctional versions of other proteins, or insufficient amounts of yet other proteins; the end result is disease. For example, diabetes is the result of the insufficient production and regulation of the protein insulin. Such conditions can be caused either by a single gene, a number of genes working in tandem, or through a combination of genetic, behavioral and environmental causes.

enhancement are included under the rubric gene therapy. But enhancement is beyond the traditional jurisdiction of medicine and is difficult to warrant as “therapy.”

¹⁴The original objective of the Human Genome Project, the $3 billion, 15-year federally funded research project under the auspices of the National Institutes of Health, was to “map and sequence” the human genome. To “map” the human genome means to determine the location of the 100,000 genes on the chromosomes. To “sequence” the human genome means to determine the nucleotide sequence (the...ATGCGCTAATGCGCTAATAGCAT...) of each of those 100,000 genes. Since its initiation, the objective of the project has been scaled back to try to complete the “map” within the 15-year time frame.
These fundamentals of genetics suggested the first procedure in the repertoire of genetic medicine: genetic testing or screening. Genetic testing assays the chromosomes of adults and children, fetuses, and "pre-embryos" to determine possible gene variations which may correlate with diseases. The testing of children and adults has three stated objectives: (1) to suggest lifestyle changes that might forestall the manifestation of disease or to suggest ongoing monitoring of symptoms; (2) to help individuals or couples make decisions about whether or not to have children; and (3) to help individuals plan their futures. The testing of fetuses and "pre-embryos" presupposes the possibility of "therapeutic" abortion, although in some instances it is undertaken in order that parents can ready themselves for their child's condition.

Genetic testing is neither simple nor straightforward. Clinicians can only test for known genes; a clear report does not completely assure freedom from possible genetic disease. Even with known genes, however, as with all medical tests, false positives and false negatives can occur, both of which can be potentially devastating (especially to fetal patients). Since most conditions for which tests are available do not yet enjoy a cure or therapy, a positive test can also be potentially devastating. Moreover, a positive test does not necessarily indicate disease, but rather indicates the probability of contracting a disease or condition. Genetic regulation is not completely understood, and it is possible that other genes or environmental factors may modify the way a particular gene is expressed; thus, a condition may not occur, or its severity may vary.

Likewise, preconceptive testing also results only in probabilities. For example, if an individual possesses a gene for a genetically recessive condition, she must marry with an individual who also possesses a gene for the same condition, and then there is only a 25% chance that their offspring will manifest the condition. In cases where one parent possesses two recessive genes and manifests the condition, the likelihood rises only to 50%. For conditions that are autosomal dominant—i.e., only one "defective" gene is required for the expression of the disease, an example of which would be Huntington's disease—again there is only a 50% chance that a child will be afflicted. And again, in many cases the severity of the expression of the condition can vary, influenced by other genetic and environment factors.

Although the rhetoric surrounding the pursuit of genetic knowledge cites as its warrant the decrease of suffering, the increase of health and choices, and the conquest of disease, at this point genetics can do little more than diagnose, predict, identify. As mentioned, for most of the conditions it diagnoses, no cures and few therapies are possible. However, for some conditions correlated with the absence or underexpression of a particular gene, initial experiments in "gene therapy" have recently proved successful.

Generally, genetic testing refers to the testing of an individual, and genetic screening refers to the mass testing of populations or groups.
The first clinical trial in gene therapy was begun September 1990 at the National Institutes of Health, targeting a disease called severe combined immunodeficiency (SCID) or ADA deficiency. Other remedies to ADA deficiency are available, but since they are not always effective, researchers hypothesized that ADA deficiency might be treated by gene therapy by removing an affected patient’s bone marrow cells, inserting normal genes for the enzyme into them, and returning the treated cells to the patient’s body, where they could grow and perhaps produce enough of the needed enzyme to degrade the toxic chemicals, thus restoring immune function.

In the first gene therapy experiment, the ADA gene was inserted into the DNA of the white blood cells by what is called a “murine retroviral vector,” a genetically engineered mouse virus. The procedure was successful: the transformed cells produced enough ADA to relieve the patient’s severe immune deficiency even better than daily injections of the enzyme. The success of the ADA trials has led to the approval of seventeen further clinical trials of genetic therapy experimentation to test protocols for other conditions.

16 See Charles Marwick, “As Number of Trials Increases, Gene Therapy Begins to Look Promising for Medicine’s Future,” Journal of the American Medical Association 267.21 (June 3, 1992): 2854–2855. ADA deficiency, a relatively rare condition affecting about twenty people worldwide, usually causes death before the age of two years. Persons with this condition lack the enzyme adenosine deaminase (ADA), required to destroy toxic chemicals in white blood cells. Without it, white blood cells die and the immune system ceases to function. In ADA deficiency, the nucleotide sequence in the ADA gene is abnormal, usually caused by a mutation rather than inheritance. The mutation could be in the form of erroneous replacement of as little as one nucleotide by another or by the loss (or addition) of one or more nucleotides somewhere in the sequence. The altered sequence encodes an abnormal enzyme that does not function or causes insufficient production of ADA.

17 Retroviruses, like viruses, are essentially packets of DNA. They function by breaching a cell’s external membrane, inserting their own DNA into the genomes of invaded cells, and reproducing themselves when the host cell reproduces. A mouse virus, however, does not exhibit pathological characteristics in human beings.

18 Over the next few years, one of the greatest areas of expansion in human gene therapy experimentation will probably be in the treatment of cancer. (See Natalie Angier, “Scientists Report Novel Therapy for Brain Tumors,” New York Times, June 12, 1992, p. A12.) A novel and accidental protocol was reported in June 1992 for the treatment of brain tumors. Based on experiments with mice, researchers will inject genetically altered mouse skin cells into a patient’s brain tumor. These cells have been designed to serve as virus factories, releasing steady pulses of harmless viruses into the surrounding tumor mass, where they can infect the tumor cells in the manner just described. Each of the viruses will carry a copy of a gene from a herpes virus which should make the infected tumor cells susceptible to a potent anti-herpes drug called ganciclovir. The viruses will be given a week to infect the tumor cells, and then the patient will be given ganciclovir, which should kill the tumor cells. What makes this experiment particularly remarkable is its specificity. The delivery viruses can only invade cells that divide. Brain cells do not divide, while tumor cells often reproduce at an expedited rate. Thus, the ganciclovir will only affect tumor cells and the normal brain tissue will not be harmed.

In the first gene therapy experiment, the ADA gene was inserted into the DNA of the white blood cells by what is called a “murine retroviral vector,” a genetically engineered mouse virus. The procedure was successful: the transformed cells produced enough ADA to relieve the patient’s severe immune deficiency even better than daily injections of the enzyme. The success of the ADA trials has led to the approval of seventeen further clinical trials of genetic therapy experimentation to test protocols for other conditions.
This and similar approaches to genetic therapy are called somatic gene therapy, which works with the cells of an individual's body. An alternative approach is called germline or gametic gene therapy. In these procedures, technicians intervene in the genomes of either human gametes—sperm and ova—or of the cells of an early embryo. In somatic gene therapy, treatment affects only targeted cells in the patient's body, does not necessarily alter a person's genetic makeup, and functions like other therapies in that it needs to be periodically repeated; changes induced would not be passed on to children. Germline alteration, on the other hand, would produce genetic changes in all cells in the body (including an individual's reproductive cells), would introduce or remove characteristics on a permanent basis, and would not require repetitive interventions; these changes would be passed on to children.

To date, germline genetic intervention in humans is not technically possible, and the use of somatic gene therapy is extremely limited. In its somatic form, gene therapy differs little from other types of therapeutic interventions. Concerns about somatic genetic therapy are primarily questions of medical feasibility and risk of side effects: "What are the alternative methods of treatment? Is gene therapy likely to be more effective, less costly, safer, or otherwise more acceptable than available alternatives?" "How safe is the procedure? What are the data on short-term and long-term consequences?" "What are the side effects of the treatment and are they reversible or treatable?" These are, for the most part, practical questions.

"Germline" genetic intervention, however, raises very different questions, not only, or even primarily, medical, but ethical, philosophical, social and theological. Advocates of human germline intervention generally invoke three justifications. They argue that not all genetic defects can be corrected through somatic interventions. Secondly, they argue that germline genetic intervention could eliminate the need for repeated prenatal diagnosis and selective abortion in genetically at-risk families. Third, they argue that it could eliminate the need for repeated somatic gene therapy from generation to generation. Thus, their arguments draw on the warrants of freedom, necessity, and utility. Further, some advocates extend these arguments to recommend not only therapeutic carried out, the brain tumors completely vanished in eleven and regressed significantly in the other three.

19Allen Verhey has noted that the public debate surrounding the ethical dimensions of genetics has generally been limited to two issues: freedom and the weighing of risks and benefits (utility) ("The Morality of Genetic Engineering," Christian Scholar's Review 14 (1985): 124-139). I think the current idiom for these two issues is choice and control. This focus engenders at least two problems. First, it masks the kind of assumptions that lie behind notions of freedom and utility—about the future, technology, nature, of our relationships to each other. Second, it shortcircuits reflection on more fundamental questions, namely, questions about "the sorts of persons we would be and become or about the kind of society we would be or become" (Ibid., p. 126).
interventions but interventions to enhance an individual’s (and their successor’s) capabilities.

Those who oppose germline interventions likewise do so on a number of grounds. Opponents challenge the rhetoric of control that surrounds germline intervention. On the one hand, given our limited knowledge of genetic interactions, in developing these technologies, errors will occur, errors that are impossible to foresee and that may severely harm the future individuals involved. Again, given our limited knowledge of genetic interactions, it is not yet possible to foresee how changes in one part of an individual’s genetic component may change the expression of another part. These changes may be perceived as benign, but we have yet to explore the meaning of so intentionally shaping the genetic component of a person’s identity and personality. True “control” is not a possibility. But should it be desired? What is the relationship between my control exercised in the creation of another individual and the other’s autonomy or freedom? Should we be exercising this kind of control over our progeny? On what grounds? Have we yet exhibited that we are capable of the kind of wisdom and humanity that would authorize this kind of paternalistic exercise? Can mere desire, want, consumer taste provide sufficient guidance or authority?

A third piece of genetic medicine is genetically engineered pharmaceuticals. Just as geneticists can insert a gene into a cell and have it produce a specific protein in a patient’s body, in some instances they can do this in vitro, synthetically producing large quantities of scarce biological compounds and receptor-selective drugs. Current examples of such genetically engineered pharmaceuticals would be insulin and growth hormone, among the dozen or so currently available. While the health benefits of many of these pharmaceuticals are readily apparent, this pharmaceutical armamentarium raises questions similar to those raised by somatic gene therapy, primarily questions of cost, access, and allocation of resources.

III. Contested Issues: Identity, Children, Power, Social Justice

Given the nature of genetic medicine, medical intervention in the lives of individuals will likely begin earlier and be more constant: they will be routinely screened as fetuses; any potential genetic condition will be monitored over the course of a lifetime; if indicated, genetic therapy might be attempted; as new genes are discovered, individuals may need to be screened again, perhaps on a regular basis; their fetuses will be screened; increasing numbers of pharmaceuticals will be produced through genetic techniques, and so on.

At present, however, individuals are for the most part confronted with simple genetic information—“your fetus possesses an extra chromosome” or “you possess a gene implicated in breast cancer” or “you possess the gene for Huntington’s chorea.” In spite of claims to neutrality and canons of “non-directiveness,” such information tends to carry its own implications: “You should...”
abort the fetus, spare it suffering, spare yourself the burden, and spare society the expense"; "We would advise prophylactic mastectomy"; or "You should get your affairs in order and inform your children; assisted suicide is available should you come near to losing your autonomy." While presented as "choices," these implications, and others like them, gather momentum toward social normativity and become increasingly "self-evident" (the choice of the "reasonable" person) as they are increasingly practiced.

These implications emerge out of a complex of anthropological, sociological and metaphysical commitments situated in a related structure of social practices. When, however, genetic information is considered in the context of community structured according to different practices and beliefs, the given implications are not quite as "self-evident." For those who consider genetic information in the context of a Christian community and its anthropological, theological, and sociological convictions and practices, alternative implications tend to emerge. In this section, I would like to consider four elements in a vision of human flourishing where the vision of genetic science and the vision of the Christian tradition differ: (1) identity; (2) children, strangers, and others; (3) control and power; and (4) social justice.

1. The Nature of Identity

Those who write on the ethical and religious dimensions of genetics frequently cite the statement by James D. Watson, co-discoverer of the double-helix shape of DNA and former director of the Human Genome Project, that the project's goal is "to find out what human being is." This question is clearly a deeply religious one. At one seminar I attended on genetics, for example, we were informed that each individual has up to twenty defective genes in their genome; translation: everyone is defective. It seemed to be the biological version of original sin, with genetic therapy as the Pelagian savior. A related cohort are the genetic determinists, those who affirm that one's genome is one's destiny; here we meet the biological equivalent of predestination.

Many understand "what human being is" to be equivalent to the theological or philosophical concept of human nature. This raises two concerns: (1) that germline genetic interventions or human transgenic experiments might fundamentally alter what makes us human, might alter our "cerebral cortex and central nervous system capable of self-consciousness, enquiry, rational ordering and analysis, moral judgment and choice"; and (2) the implicit claim that, given the equation of the human genome with "what human being is" and human nature, the Human Genome Project will produce a genetic definition of the "normal" human being.

Both notions are thickly laden with particular convictions about what should be valued. The content of the "human" varies with history and culture. Likewise with the "normal." While it may be possible to determine an average or common genetic distribution, in many conversations a not so subtle shift occurs between notions of "normal" and notions of "normative." What if geneticists determine that part of the normal human genetic complement is a gene for adultery? Is it therefore normative? On what basis do or will we decide which characteristics are "human," "normal" and "undesirable"? What is to decide this? How quickly does "ideal" elide into "normal"? How do social structures and ideologies of "normalcy" reinforce each other?

Correlating religious doctrine and genetic science is a tricky affair. Here I will avoid discussing the epistemological issues and mention two practical problems. The most obvious problem is the one that has affected all attempts to discuss human nature: historically, socially, and culturally constructed concepts are read into nature or human biology, and human biology is then used as a warrant to provide an "objective" basis for a socially constructed belief or position. For example, Ronald Cole-Turner has attempted to correlate genetics and notions of free will and predestination:

Correlations between genes and behavior, which will multiply as the genome project goes forward, are remarkably compatible with the more traditional view of original sin as a disordering of the will. According to this traditional view, it is not merely that the will struggles against an unruly body. The will itself is disordered and does not do what it wants to do. Paul's self-described "wretched man" (Romans 7:24) is consonant with the insight emerging from genetics. Our whole being, including the center of our personhood together with its will, is influenced by our genes.

...Our genes carry the legacy of our evolution; and our personhood itself, including our capacities for consciousness, moral decision, and faith, arises from our genes as selected by evolution. Specific decisions and beliefs, of course, are not carried genetically. But our genes apparently do carry our individual inclination toward broad categories of attitude, religiosity, and behavior...In time, we will come to see how our individual genotype influences not merely our eye color but our social attitudes, behaviors, and religious activities...Our souls are as different as our bodies.

Perhaps faith is a mutant version of reason.

A second problem arises when science is equated with objective, value-neutral, indisputable fact. Then, in trying to create a "fit" between a religious belief and a scientific position, the religious belief must give way. Again, Cole-Turner illustrates this:

Christianity has assumed that all are morally and spiritually equal. All have sinned, all stand in need of grace, and all have the same degree of need and of capacity for salvation. All have the same moral capability, and all are equally responsible for their behavior. Thanks to research in genetics, we are learning that this presumption of equality no longer holds...We will learn how we vary in our capacity for moral and religious behaviors...Needless to say, our theology must begin with a new axiom—namely, that we are all individual before God, with a unique set of genes and a unique set of moral and

---

spiritual needs and capabilities. Salvation must be personalized as well as personal. Individual differences must be affirmed, not discriminated against... [Thus] a growing awareness of our genetic individuality should prompt us to rethink the idea of redemption... [Our] genes, and not merely our life histories, affect the form of our redemption. In the future, the doctrines of salvation and of the spiritual life will need to recognize individual variation.2

For Christians, normativity, identity and the meaning of the “human” derive from sources other than genetics, sources which serve to interpret genetic information rather than vice versa. Christians affirm through worship, practice, and story that identity is not determined by one’s relationship to one’s genome but rather by one’s relationship to God and to God’s cause. Through baptism, we are “born again,” born into a new life and a new identity. Creation is not negated but is recreated; the identity derived from one’s genetic component is now normed by the identity given through baptism, by being engrafted into the body of Christ in eucharist, by following a call to discipleship.

This approach to identity may help counter a number of disconcerting social trends. It will counter the myth of the genetic ideal by locating the description of an “ideal” life in relationship with God and community. It will counter the trend toward genetic uniformity by creating a framework that values and thereby prefers diversity (“We, though many, are one”). It will help remind us that “who we are” is only in small part constituted by our nature and genetic heritage: a good deal depends on “who is with us” through our growth and life, the conditions under which we grow, and “what we do” or “how we live” with our inheritance.

2. Attitudes toward Children, Strangers and Others

Current genetic testing largely involves screening the genetic makeup of embryos and fetuses with the assumption that the genetically “defective” will be either aborted (if they are in utero) or not implanted (if they are in vitro). Claims are beginning to be made that “couples have no obligation to produce genetically defective offspring” or that couples—or individuals—have a “right” to produce children free from genetic defects. Germline genetic interventions—both therapeutic and enhancing—are increasingly championed.

If genetic technologies make it increasingly easy to assay an embryo’s genetic makeup, and individuals are persuaded to abort “undesirable” fetuses, it is conceivable that society will look less favorably on those who choose either not to have their children screened or who, in light of screening, choose to bring these children to life. It is also conceivable that our utilitarian, bottom-line, efficiency-dominated society will be less and less likely to provide the financial and communal support for these children and their families when they are clearly “products” of choice and not chance. Decisions to give birth to imperfect children may become understood as “socially irresponsible.” Abortions of the

"defective" may even begin to be understood as "morally responsible," insofar as the autonomy of these defective fetuses may be compromised significantly, and they may be subjected to suffering.24

In the course of perfecting germline techniques, mistakes will be made which can produce lasting harms. What do we do then? If mistakes are introduced into an embryo’s genetic makeup, two courses of action are open: simple destruction of "failures" or the killing-abortion of abnormal fetuses whose phenotypes do not correspond to initial expectations. Many scientists would understand the implanting of a "defective" blastocyst as a mistake and a waste of resources; they would prefer to have a "successful" outcome of the procedure. To proceed in the area of germline experimentation will entail the conscious acceptance that some embryos will be created solely as experimental material and others will necessarily be sacrificed for the sake of something else—science, others, etc. Not only is it questionable to use other, even potential, persons as means to an uncertain end, but it is questionable whether we should accept the assumption that genetically altered but defective embryos should be destroyed. What is the moral status of the "defective" unborn?

In the face of these technologies, Christians will need to revisit their theological understanding of children. This understanding will be informed by affirmations that life—and therefore children—are gifts.25 This understanding of children will likewise be informed by the practice of baptism, in which parents give their children over to death that they may be born anew as God’s children called to serve God’s kingdom. God’s purposes for our children—and for us through our children—may well be different from our purposes for our children and ourselves.

Congregations will need to examine as well the role children play in their common life, and the ways in which the life and social commitments of the community enable its members to welcome the other, the stranger, and those who

24 We can find evidence of this position in, again, Ronald Cole-Turner: "[W]hen it is a question of the genetic health of the unborn, in most genetic diseases there are only two medical interventions, pregnancy prevention and pregnancy termination.... Couples at risk who do not wish to forgo having offspring, and all other couples who are not screened, and conceive a child with a genetic defect, are left with the only remaining option: abortion" ("Religion and the Human Genome," p. 165). Clearly, bearing, welcoming and raising the child is not an option. He continues: "To do nothing (that is, to allow the pregnancy to continue) is to choose that a life of pain be allowed to continue to the point that the pain is experienced. It is to withdraw the only available act of mercy. But the only act we can offer is to terminate the prospects of an individual human life, precious to God even if destined to painful brevity" (Ibid., 166). To be clear, Cole-Turner does not limit these statements only to genetic diseases that promise severe and unrelenting pain; they are general.

25 For fuller discussions of the meaning of children see Verhey, "Morality of Genetic Engineering," and Stanley Hauerwas, Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church (Notre Dame, Ind.: University of Notre Dame Press, 1986); Truthfulness and Tragedy (Notre Dame, Ind.: University of Notre Dame Press, 1977); and Vision and Virtue (Notre Dame, Ind.: University of Notre Dame Press, 1974).
are less than perfect. Does the congregation integrate or marginalize those who are not "normal" or "successful" or "perfect" and thereby make it more difficult for parents to welcome a child who is different? These practices and beliefs, in conjunction with Christian commitments to serving the needy, the marginalized, the outcast, to welcoming the stranger in hospitality, provide resources for individuals faced with decisions to submit their fetuses to genetic testing.

3. Control and Power

Genetics is equipping us with powerful tools for determining our own future, as well as that of our children and our environment. Some are hopeful in the face of these new powers:

God has put into our hands the possibility of what has so long been demanded by the great world religions, a change in man himself... To succeed will be to begin a new and glorious stage in the history of what has been so defective a humanity.26

Others foresee in the powers of genetics the destruction of humanity, either by some alteration in the fundamental genetic basis of human nature or by a reduction of genetic diversity. The vehicle for this putative salvation or perdition is genetic technology. But the effects of technology need not be so apocalyptic to require serious consideration.

Technology, far from being a neutral tool amenable to human purposes, changes us as we use it. As Allen Verhey has noted, "although technologies are introduced as increasing our options, they can quickly become socially enforced. The automobile was introduced as an option to the horse, but try to ride a horse home on the interstate and you'll find yourself in trouble."27 In a culture increasingly unable to engage in moral discourse, technological fixes become the remedy of choice for social problems. Moreover, technology may further exacerbate the social conditions which give rise to the problems. For example, the abortion pill—RU 486—may make abortion quicker and less painful, but by removing the symptom—unwanted pregnancy—it may well deflect attention from the underlying problem, namely, that 1.5 million American women and girls each year find themselves pregnant when they do not want to be and feel compelled to abort their children.

Most technological advances are heralded as methods for controlling the contingencies of nature and for increasing the range of human choices. Be it the problems of geography, pregnancy, or disease, technology is a vehicle for making nature amenable to human purposes. These questions of control are questions of power—power over those deemed "defective," power over our children, power over ourselves, power over nature. Power is also pursued under the auspices of


the Human Genome Project, for by acquiring this knowledge some will inevitably be charged with power over others.

In contrast to both of these positions, in Scripture, creed and worship, Christians daily affirm different understandings of control and power. Davis' long-awaited transformation of humanity is affirmed to be ultimately an eschatological event; certainly, humanity can change humanity but not necessarily for the better. Christianity affirms that the remedy of the spiritual and moral defect that plagues humanity will be a matter of God's doing in God's time. Scripturally and theologically, there is an infinite qualitative difference between the transformation of humanity wrought by humanity and the transformation of humanity promised and wrought by God.

Christians are called to avoid worshiping the "false idol of technology." But they are also called to be disciples, to pursue God's purposes in the world responsibly, such as healing the sick and attending to the sufferer. In these pursuits, Christians employ technology. To employ technology with integrity will require that clergy and congregations together reflect on the relationship between God's agency and human agency as well as the meanings and temptations of technology. Christian reflection on technology as such will entail Christian reflection on the relationship between humanity and nature. Are we stewards, co-creators, or "created co-creators"? At each step, when confronted with each new technology, Christians will need to ask themselves whether the kinds of power offered are compatible with the kind of power practiced by God and witnessed to in the Christian story of a God who redeemed humanity through suffering on a cross and whose power is made perfect in weakness.

This mention of "created co-creators" raises another issue. Discussion of genetic technologies and their attendant ethical analyses is often short-circuited by recourse to "bad axioms" or slogans, one of the most common of which is "playing God." Although often invoked, the meaning of this phrase has received scant treatment. C. Keith Boone reminds us that as with most bad axioms, although employed in the place of a sufficient argument, the slogan "playing God" points toward a kernel of truth that warrants closer inspection. In bioethics in general, agents are accused of "playing God" in situations involving decisions about who lives and who dies. Likewise in genetics, the slogan arises in two contexts, although primarily in the second—whether to abort genetically "defective" fetuses (i.e., who dies?) and regarding the manipulation of the germline, whether nonhuman or human (i.e., who—or sometimes, what—lives?). The ability to create potentially new life forms or new human individuality seems analogous to the power premised of God in the attribute "Creator."

There are a number of problems with the notion of “playing God.” On the one hand, as Christians, we are called to “play God,” to model ourselves as closely to God as possible. While the notion of “play” may, of course, carry more flippant connotations than the phrases “be obedient to” or “follow” or “to be disciples,” we invariably look to God’s character to find the essence of the human, the “imago dei.” In discussions of genetics, the most frequently invoked divine characteristic is God’s creativity, in which many find a call to and a model for our own creativity, identifying creativity as the “imago dei” and the essence of human being as “created co-creators.”

The reason that the slogan “playing God” is unhelpful, then, is not that this activity of creativity is forbidden. Rather, the problem is that the God Christians are called to follow is a very different God. The slogan “playing God” reduces the identity of God to a single characteristic—e.g., the power to create—from a single biblical story found in the book of Genesis. The God imaged in “playing God” is the God of the Enlightenment, the same God who renders the modern “theodicy” question so problematic. This God—omniscient, omnipotent, omnipresent, eternal, unchanging—is not the God known in and through Jesus Christ. The Enlightenment God emerges when “religion” is conceived generically, abstracted from its stories, histories, and particularities, presented as tolerant, universal, and nonoffensive for the purpose of “dialogue.”

Christians, however, know that ultimately they cannot really play God. God’s power to create ex nihilo and to make a new heaven and new earth in the future is conceptually as well as practically unavailable to humanity. We constantly exercise our ability to create and recreate—new persons, new species, new conformations of nature. Yet no matter how proficient we become at manipulating created matter, the form of our creative endeavor will be qualitatively different from that we affirm of God.

Thus, while the slogan “playing God” fails to refute a particular endeavor, neither does the recognition of our call to be creative—our status as “created co-creators”—render a blanket sanction. The vision of God’s creativity epitomized in the Genesis stories must be held in tension with other biblical images: suffering servant, resurrected savior, Body of Christ. The kernel of truth hidden in the slogan is thus quite different from the way the slogan is employed:

In the Jewish and Christian traditions “playing God” is associated with pride and arrogance, the aping of divine power, or the attempt to gain salvation without the help of divinity. It is not the use of power and creativity that offends but rather attributing power to one’s own resources. “[P]laying God” is not, in this usage, an act against morality, but rather one against faith. Yet these traditions might well morally object to... problems with human conceits about our ability to predict or control the outcomes of our actions.31

30See Stanley Hauerwas’s discussion of this notion of God in Naming the Silences: God, Medicine, and the Problems of Suffering (Grand Rapids: Eerdmans, 1990).
4. Social Justice

Basic primary health services are unavailable to large portions of the U.S. population (over 10%); the statistics for world health are even more dismal.\(^3\) Yet the federal government has committed to spend $3 billion over 15 years—$200 million per year—on the Human Genome Project. Private concerns, including the biotechnology industry, have committed even more funds. Genetic biotech companies are making huge sums of money; their activity in the stock market has made millions more for other investors. Yet scientists are not unanimous in the scientific or medical merit of the Human Genome Project or its ability to meet its goals within its timeline or budget.

Is it just to allocate this magnitude of resources to genetics when it is well known that the primary cause of morbidity and mortality worldwide is poverty, when millions of people around the world have no access to the basics of modern medicine—sanitation, antibiotics, vaccines? It is estimated that only 5% of the genome contains genes correlated with disease conditions; is the investment in the Human Genome Project proportional to its health benefits? Allied to these questions are other questions of allocation, questions of the allocation of costs and benefits. Who pays the costs and reaps the benefits? Not necessarily the same persons. It has been argued that one sector of our population—that of the unborn—currently incurs a disproportionate burden of harm, insofar as some embryos are created solely for research purposes while others deemed inferior or "defective" are discarded. Moreover, given the emphasis on screening or altering nascent life, there will be an undue impact of these technologies on women (just as women already bear the bulk of the social cost of caring for those with genetic conditions).

The current structure of health care is grossly unjust. Because of limited access to health care among many populations—especially urban and poor—health problems become concentrated in these communities. For example, they experience higher infant mortality and decreased life expectancy. As gene therapy becomes more widely practiced, we can only expect that these injustices will be exacerbated. Somatic gene therapy will likely be expensive and available primarily to those whose health insurance will cover it, and the same is true for genetically-engineered pharmaceuticals. Enhancement programs would further compound the gross inequalities and discriminatory practices that constitute our

\(^{3}\)To quote from the Christian Medical Commission of the World Council of Churches: "In Asia, Africa, the Pacific and Latin America... Seventy percent of the people live below the poverty line with little access to services like health, education, housing, land, food, and stable jobs... In Brazil, for example, 6 million of the 10 million mentally ill are children, and 500,000 children die of malnutrition every year. Eighty-five percent of the 450 million people in the world who suffer from disability come from developing countries, which have only 2% of the resources to treat and care for disabilities" (Healing and Wholeness: The Churches’ Role in Health [Geneva: Christian Medical Commission, 1990], pp. 24–25).
culture, insofar as those with power and means will choose what characteristics will be valued, and those characteristics will undergird their own social power. This may well concentrate genetic problems and genetically-related diseases, conditions, and attributes in economically-disadvantaged sectors of the population, exacerbating social class distinctions and likely racial distinctions as well.

In the face of these statistics, it is difficult to justify a blanket recommendation to "religious groups to advocate access to reliable genetic information and counseling services...." When members of religious communities take what they know of God, identity, children, strangers, control and power, learned from their activities of worship and common life, into the world of their everyday activities, they will likely not turn into genetic lobbyists. Rather, activities of Christian social ministry in the age and culture of genetics will more likely resemble activities of Christian social ministry prior to the advent of genetics: welcoming and caring for the marginalized, the sick, the less than perfect; working for justice for those who are oppressed and voiceless; identifying attitudes and practices which exacerbate unjust social structures; living in ways consistent with their convictions, and supporting others in this difficult task.

IV. Conclusion

For those of us raised in a scientific culture, and even more for those of us trained as scientists, it is difficult not to be dazzled by the abilities and potential of genetics. Gene therapy seems to hold promise equal to that of penicillin. To understand the quiet, constant and microscopic activities of chromosomes, DNA, genes and their cross-generation effects, is to be awed, for some humbled, and for those who find pleasure in understanding, to be gratified.

But those who likewise know from recent history and personal experience the proclivities of human beings and Western culture, and who find themselves shaped by the stories, the convictions, the self-understandings of the Christian community, rightly pause—to learn more, to consider together, to discuss, to pray, to evaluate. The advent of genetic medicine does indeed call theologians, clergy, and lay persons as well to re-examine their interpretations of creation, human nature, moral choices, the character of God, and some interpretations may emerge as inadequate or ill-formed; some, however, will emerge with new power and relevance. Genetic medicine challenges us to renew the practice of moral discourse and to renew the congregation as the place where it occurs. Without such a practice or a place, congregants will be ill-equipped to live differently in the face of the powerful, often utilitarian, interpretations and implications presented to them by genetic medicine.