

GENETICS AND EUTHANASIA IN A FREE SOCIETY:

AN APPLICATION OF FLEW'S GOOD FAITH

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Abstract:

This essay is about two major issues in biomedical ethics, genetics and euthanasia. But it is also about the problem of ideological distortion in public discourse. There exists a negative form of ideology, i.e., a systematic omission from conversation of large parts of empirical reality, coupled with distorting analogies and metaphors, with the intention of supporting unsupportable positions. In such a world, self-interest and class-interest sweep aside factual truth and logic. Fixed litanies and fleeting media images are conjoined with a failure of educational institutions to convey accurate history. We begin to wonder if modernity can remain free from demagogues. In part, this essay is a case study of two areas where good faith in factual truth and reason has dissipated, that is, in the debates over genetics and euthanasia.

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In a pluralistic culture with competing Weltanschauung, acrimonious debate is commonplace as disparate communities of interpretation compete for dominance in the public square. Calls for civility and mutually respectful conversation abound, but civility is a thin veneer over a boiling cauldron. In the throes of competition, glaring ideological distortions run rampant. I use the word "ideological" in the most negative sense: a systematic omission from conversation of large parts of empirical reality, coupled with distorting analogies and metaphors, with the intention of supporting unsupportable positions. In such a world, self-interest and class-interest sweep aside factual truth and logic. Fixed litanies and fleeting television images are conjoined with a failure of educational institutions to convey accurate history. We begin to wonder if modernity can remain free from demagogues. In part, this essay is a case study of two areas where good faith in factual truth and reason has dissipated, that is, in the debates over genetics and euthanasia.

Additionally, this is an essay about the perennial tension between the One and the Many, or the particular and the universal, with respect to moral values. Even in a pluralistic culture it is possible to accept common minimal principles of ethics such as nonmaleficence, autonomy and justice, but when these universal

principles are applied through the filters of many interpretive worldviews, considerable moral relativism persists. For example, we may all agree on the principle of nonmaleficence ("do no harm"), but disagree on whether this principle applies to the human fetus at birth, at quickening, at viability, or even at birth. We may disagree about who is dead and therefore no longer under the protective umbrella of nonmaleficence, for some accept whole brain definitions of death, and some cling to traditional views (e.g., Orthodox Jews and most Japanese). We may hold to egalitarianism with respect to sentient species, so that our eating the meat of nonhuman animals is judged pernicious. My point is obvious: consensus about a principle of ethics does not eliminate moral relativism, due to the central place of interpretation or hermeneutics in valuing life. The most we can sometimes hope for is a civil conversation across traditions of disparate interpretation, one that avoids acrimony and distortion.

In the field of biomedical ethics, there are at least two major issues for the 1990's: genetics or the Human Genome Project, and euthanasia or mercy killing. With respect to genetic information, it has been argued that anyone should have any and all information he or she desires in the context of both prenatal and presymptomatic carrier screening. With respect to euthanasia, it has been argued that any competent human being has a right to decide on the moment of death, and to implement said desire either through assisted suicide or mercy killing. I will suggest that in both these areas ideological distortions occur.

1. The Human Genome Project and Genetic Testing

The project to map and sequence the human genome is driven by the hope for gene therapies to ameliorate or cure human diseases. Almost weekly the media reports a new discovery such as the gene responsible for congestive heart failure, Huntington disease, or familial Alzheimer disease. These discoveries are heralded as potentially important therapeutically. The National Center for Human Genome Research of the National Institutes of Health (United States) is engaged in a worldwide research program known as the Human Genome Project. Its goal is to map the entire DNA content of the human being.

One concern is with the distortion known as genetic determinism, which overstates the extent to which human disease is genetically determined. Since the late 1950s, a rapid expansion of knowledge as to how genes work has resulted in the myth that through genetics utopia is on the horizon. For example, despite weak evidence, the "criminal chromosome" myth captured the public imagination. But it was soon clear that the XXY genetic configuration resulted neither in hyperaggression nor criminal behavior. However, the XXY myth was already embedded in high school and medical school texts.

Increasingly, the focus on the human genome in basic science and in the media is shifting international attention to both genetic explanations and solutions of medical or social problems. Some scientists have suggested that the Human Genome Project will solve the problem of homelessness. The presumptions are that

homelessness is due to mental illness, that all severe mental illness has a genetics basis, and that by discovery these genes cures can be developed. The field of psychiatry, long on the defense in medicine because of its empirical softness, is increasingly focusing research on genetics. This does not mean that mental illness is no longer considered multi-factorial, or that psychotherapy is outmoded; yet the quest is for a clear genetic indicator and a genetic solution. Increasingly, we see the medicalization and geneticizing of social problems rooted in family disfunction or poverty.

What we await is any clear evidence that gene therapy will work. Moreover, we seldom hear of the morally questionable aspects of gene mapping. How can therapy be clearly distinguished from enhancement, and how likely is it that medical science will avoid marketing new images of human perfection? The therapeutic repair of human beings is noble, but efforts to enhance the already healthy are inherently problematic. What defines enhancement? Are taller or more slender people better? And where would the endless so-called enhancement end? Serious and objective medical need, rather than the vicissitudes of enhancement, are the proper basis for genetic interventions. The possibility for a confusion between mere human wants, and genuine human needs, is always real. A parent may want a "designer" child via gene enhancement, but this is not something that parent or child needs.

Additionally, mapping will dramatically increase the number of gene abnormalities that can be tested for to many more within the

decade, and perhaps eventually to thousands. While selective abortion is an old topic, the genome project raises it in a newly important way. Many of us accept prenatal diagnosis and subsequent abortion for grave or relatively serious genetic defects that will manifest early in the sufferer's life, but are critical of termination of pregnancy for trivial or moderately serious genetic indications, and for indications that will manifest only later in life. Even on the premise that there is a basic right to elective abortion, of which the right to selective abortion is a subset, there is nevertheless room to discuss the moral underpinnings of the choices that women are free to make. Barbara Katz Rothman provides a number of case studies in which abortion was chosen as an alternative to a child with mild diseases and less than disabling impairments. She suggests a future in which we will see "a rise in the standards of production for children" that emerges from new technologies. "Will we," she asks, "establish a set of norms of acceptability, and then narrow, and narrow, and narrow yet again those norms" (1986, p. 227)?

In response to this potential problem, Dorothy C. Wetz and John C. Fletcher, supporters of the genome initiative, argue that the medical profession should abandon a position of ethical neutrality with regard to prenatal sex selection, partly because this sets precedents for selective abortions unrelated to disease or disability, e.g., eye and hair color, thinness, skin color, straight teeth, and other "cosmetic" considerations. Within a decade or two, they continue, these "exotic" choices will be

technically possible, especially relating to body size and height (1989).

Prenatal testing will eventually be capable of detecting hundreds or thousands of single gene defects, many more polygenic and multifactorial defects, and numerous superficial characteristics of aesthetic concern. Pregnant women, at about eight to ten weeks gestation, may be able to have a blood test indicating the DNA profile of the fetus based on fetal cells in the maternal circulation. This extensive new level of knowledge leads to tremendously complex personal choices about what lives are worth living, qualitatively considered. That women have the right to choose abortion is widely accepted in American culture, but the discussion only begins here respecting personal moral conscience in the throes of decision.

In the absence of an obviously grave and immediately threatening defect, vexing decisions will be made based on severity, probability, and age of onset of disease or disability. Adult onset polycystic kidney disease, which may or may not occur, and which results in progressive renal failure during the adult years, is treatable by dialysis or transplant. In this case, moderate severity combines with uncertainty of manifestation and late onset. Huntington's disease can be distinguished from adult onset polycystic kidney disease because it is much more severe, and untreatable. Would an abortion be morally justifiable for a fetus if the future child has a 20 percent probability of bipolar affective disorder or schizophrenia? What about familial

Alzheimer's disease? What shall we do with the freedom to decide, especially when genetic conditions have variable expression from mild to serious, variable likelihood of manifestation, and variable age of onset?

At a minimum, we can distinguish moral from aesthetic values, and give priority to the former. A disease such as Huntington's may be insufficient grounds for selective abortion because, even though it is clearly very severe, the eventual sufferer nevertheless will have many decades of good and unimpaired living. Moreover, the parents of the child are not immediately or even directly affected in the way they would be were the disease of early onset.

I do not want to go very far in resolving the balance between severity, probability, and age of onset that might justify selective abortion. Rather, I offer several humanistic reflections to provide a general background for such decisions, and that together justify reservations about abortions for diseases of late onset, such as Huntington's or possibly familial Alzheimer's. My limited intention is to comment on American culture, focusing on three themes: the parental desire to avoid bringing suffering into the world; the contingencies of the human condition; and the moral ambiguity of the quest for "perfect" babies. These themes will be linked to both selective abortion and, more briefly, to gene therapy.

Suffering: Parents rightfully prefer not to bring lives filled with suffering into the world. Few, if any, would quarrel

with the assumption that it is preferable to have healthy children who are not born into physical pain. When prenatal diagnosis reveals a grave defect that makes life an onerous burden of suffering, nonmaleficence warrants abortion. But it is wrong to assume that suffering is the necessary result of genetic defect, or that lives with degrees of physical suffering cannot be creative and meaningful.

One advocate of rights for disabled persons points out that as prenatal diagnosis results in vast new genetic knowledge, women need "to obtain far more and very different information than they very commonly get about people with disabilities" (Asch, 1989). The notion that all disabilities cause suffering is conceptually flawed. In many cases, negative stereotypes obscure the creative ways in which people with disabilities cope with different challenges and needs.

The Human Genome Project calls for scrutiny of the assumption that those who are different necessarily suffer. With our societal inclination to rather rigid standards of beauty and physical prowess, self-reliance and productivity, it is too easily assumed that those who fall short of these standards therefore suffer. Compassionate discrimination, which makes the experience of genetic impairments out to be worse than it is, should be avoided.

The desire to eliminate disease and the sufferings that may be associated with illness is morally valid. However, the definition of suffering is wrongly expanded to include the ways in which an individual is different from others, though fully healthy.

Suffering becomes a social construct imposed on us, so that parents will petition the physician to "enhance" a child regardless of the onerous imposition on the "patient" and the folly of the request. It is incumbent on physicians to hold firmly against the quest for enhancement, in part by maintaining a disease-based definition of the human suffering for which medical therapy is responsible. To widen the definition of suffering so as to provide enhancement interventions is precisely the wrong response to the human condition. Moreover, such interventions violate the purpose of the healing art, which is the restoration of physical and mental function when possible.

Contingency: Human experience is partly uncontrollable, and therefore contingent or chance-ridden. Our desire not to bring suffering into the world must be tempered by a recognition that suffering is a part of life, and escapes human prevention to a large degree. Those who are genotypically and phenotypically more "perfect" than others can lead tragic lives, however much we try to prevent this. Take the case of the great French artist Henri de Toulouse-Lautrec. A descendent of aristocrats, he was the victim of two accidents which broke his legs and left him incurably disabled. His torso developed, but not his legs, and he became deformed, unable to walk without a cane. He derived some consolation from painting, until dipsomania led to the asylum.

His was an irregular life, one of immense suffering; it was also one of creative compensation and the development of the artistic poster as we know it today. Toulouse-Lautres was born a

what Leslie A. Fiedler dubs "the tyranny of the normal." Fiedler notes a "deep ambivalence toward fellow creatures who are perceived at any given moment as disturbingly deviant, outside currently acceptable physiological norms." He refers to "a vestigial primitive fear of the abnormal, exacerbated by guilt." Fiedler fears the "enforced physiological normalcy" that sent dwarfs to extermination camps in Hitler's Germany. "Perhaps it is especially important for us to realize that finally there are no normals, at a moment when we are striving desperately to eliminate freaks, to normalize the world" (1985).

One of the ways in which persons who depart from "normals" contribute to the community is by challenging us to overcome social stigmas, and to accept difference in our midst. Views of physiological human perfection are inevitably intertwined with stigmas, one form of which is abominations of the body. Those whose bodies depart negatively from the "normals" are the victims of a socially shaped tendency to revulsion. Stigmas specific to the body are as morally problematic as those related to religion, race, and nationality, and often cause great suffering to disabled people. People who are different and "imperfect" teach us about the meaning of equality and commitment. But we are beings who fear difference, so diversity is hard to sustain.

The very nature of human perfection has, of course, been the subject of acrimonious debate over the centuries. In the medieval period, there was a profound sense that perfection is chiefly a matter of character and virtue, and that bodily imperfections

provide opportunities for concentration on the internal moral and spiritual values. Indeed, the weight of religious symbolism, from the club-footed Christ figure of the Eastern Orthodox icons to Dostoyevsky's idiot epileptic savior, underscores the inward perfection made possible by external limitations.

There is treasure in earthen vessels, and earthen vessels we humans are, subject to countless infections, accidents, chronic ailments, and finally to the decline of old age and death that we in this culture try so hard to deny, as though senility were mere myth. Arguably, our culture focuses perfection on the vessel rather than on the person within it. Of course it is reasonable to avoid bringing grave human imperfection into the world. Infants with no relational potential should not be born. But we must be highly circumspect about declaring too imperfect those who must endure somewhat earlier in life the very sorts of frailties that eventually assault each one of us.

It is especially ill conceived when a society so overvalues beauty and physical prowess that ugliness and bodily weakness are aborted out of existence. Aesthetic vicissitudes might increasingly determine who should, and who should not, inhabit the world. But this determination is fundamentally flawed (the Buddha would laugh). It is rooted in mistaken attachments to the bodily container of the human self, and not to the self in its essence. Arguably, our culture is pitifully narrow in the externality of its perfectionism. We must reflect on the abyss of racial hygienics.

In particular, enhancement and eugenic genetic engineering are

problematic because they further externalize our images of human perfection, and do not result in any clear moral good. By externalized perfection I mean definitions of the human good that are centered on the shape of the body, or on some particular capacity for music, visual arts, and so forth. All the major cultures of the world have defined human perfection internally, that is, with emphasis on character and virtue. From Aristotle to Thomas Aquinas, perfection meant wisdom rooted in experience and in the relationships by which the moral life is learned through example. Our perfection lies not in gene enhancement, but in the enhancement of character.

2: The Issue of Euthanasia

A good death is no longer typically defined in terms of retrospective self-assessment and repentance, or of customary religious rituals calling together family, friends, and neighbors. A good death, "euthanasia," is increasingly defined as a direct, active, and voluntary preemptive strike against decline and dependence on others. The active, directly intended, and freely chosen self-destruction that was once unspeakable has become speakable. The debate in the United States over this issue has been in large part focused on the "slippery slope" arguments, e.g., that voluntary euthanasia will lead to nonvoluntary euthanasia (the killing of the severely demented patient, the patient in the persistent vegetative state, and so forth). This in turn will lead to involuntary euthanasia, i.e., killing people against their

wills. At the center of this ideological flurry is the Nazi analogy. Any physician who assists in a voluntary patient suicide is considered a Josef Mengele waiting to happen. My view is that the Nazi analogy is used to grease a slippery slope that is in fact not terribly slippery at all. In other words, it is reasonable to think that certain clear steps could be built to prevent the fabled slide into the moral abyss. This does not mean that I advocate assisted suicide or mercy killing, but that I do not believe that slippery slope arguments and Nazi analogies are very persuasive.

The obstacle to the progress of the euthanasia movement in Great Britain and America was the abyss of the Nazi eugenics movement, and the appalling revelations of medical killing at the Nuremberg Tribunal. Yet now, with Holland and the Royal Dutch Medical Association placing de facto imprimatur on euthanasia, with the growth of the Hemlock Society (and its political wing, Americans Against Human Suffering), with revelations in major medical journals by physicians who have killed their patients, with Dr. Jack Kevorkian's suicide machine, and with a 1990 Time/CNN poll indicating that 57% of Americans approve of physicians administering lethal injections to unconscious terminally ill patients who have indicated this preference by advance directive, the times are changing.

My response to this movement toward euthanasia is cultural, rather than philosophical-analytical. I will comment on the themes of control, loss of care, and the desire to put an end to human suffering. These themes are not unrelated.

Control: Modern technological culture encourages ever greater control over human events. American families often want their loved ones to die in the controlled environment of the medical intensive care unit. The beeping signals and flashing lights of the machine signify a mastery over nature and human nature. For many, these machines define what is the best standard of care, and any shift away from this is downgrading and therefore undesirable. So frequently, families will resent the offer to move a dying patient from intensive care to a special care unit that provides care and comfort only. Americans often think that if they do not avail themselves of the latest technology, they are certainly "missing out."

The idea of throwing in the towel, of only leaving death in the hands of nature or of a wisdom that underlies nature, is anathema to the rage for control. We witness the same rage in our era of the "perfect" baby, and with the advent of the human genome initiative, selective abortion of all but one's idiosyncratic aesthetic image of a cosmetically ideal child will be increasingly possible. Some will want to control everything from hair color to height. DNA profiles of the fetus will be available based on fetal cells in the maternal circulation. Researchers want to control the aging process with growth hormone or scavenger cells. From the womb to the tomb, technological control is the cultural mandate. With the ars moriendi, it was the dying person's internal control over a rite of passage that brought order. This inward control has largely given way to mechanical control.

Death by lethal injection is best understood as a further act of technological control. It is driven by the will to control, to remove human events from the domain of nature, even when suffering can be mitigated in almost all cases by proper palliation. Against this form of control there is only the sense that the hour of death is rightly decided by a wisdom beyond us. To return death to the state of nature requires the assumption that underlying nature is the wisdom of God, of some higher purpose or regulation. Your ordinary Americans who oppose euthanasia appeal not to philosophical arguments, but to straightforwardly theological ones.

The technological control we do need is in pain control. New modalities of palliation that leave the patient in a reasonably clear state of consciousness are emerging. Electrodes implanted into brain or nerve can modulate pain pathways. Through surgical and cryonic neuro-ablation pain can be managed in remarkable ways. Our approach to pain management must be physical, psychological, multi-disciplinary, and spiritual. But in our curative and rescue-oriented health care system, management of pain is not a priority. Ignorance of proper pharmacologic principles is pervasive, and physicians are often ill-equipped. Medical schools do not include pain management in their core curriculum. Narcotics are administered on a pain-contingent basis, rather than on time contingency, so that we wait for the patient to express pain. This is ethically wrong.

Caring: To a degree, euthanasia is also the result of a culture that devalues caring. Our medical system concentrates on

research and training that steals people back from death. It is rescue oriented in the extreme. Merely caring suggests "acting by default." In a highly compassionate call for the recovery of caring, Daniel Callahan writes, "At the center of caring should be a commitment never to avert its eyes from, or wash its hands of, someone who is in pain or suffering, who is disabled or incompetent, who is retarded or demented; that is the most fundamental demand made upon us" (1990, p. 145). Callahan is appropriately critical of our failure to train medical students to care in the seminal sense of the word, and he is also right in his pessimism that however much care is discussed in glowing terms, "it always loses out to an emphasis on scientific knowledge and technical skills, and there is no end in sight to that bias" (p. 147). Technology has "muscle aside" the most basic expressions of care.

It was not always so. Once, there was little the nurse or physician could do but hold the dying patient's hand, usually at home, and with some religious motivations. Now, we need to recover such simplicity once rebellion against dying becomes futile.

The caring that the dying really need, other than palliative, is a compassionate response, an enduring supportive emotional intimacy. In a culture where passion is more highly valued than compassion, the tasks of caring are readily viewed as demeaning. Partial or constant dependence on others is viewed as an unreasonable imposition, and as personally demeaning, never mind that caring is a basic human need. Euthanasia has an appeal when

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