

Bioethics: Gene Therapy and The Problem of Ends

Bioethics is a subdivision of ethics. Its focus is the ethical dimensions of the biological sciences. These ethical dimensions include an examination of means (scientific processes) and ends (the consequences for humankind). It seems to me that we are giving most of our attention to issues surrounding the means and neglecting those surrounding the ends. Or at least there is a tendency to limit ethical considerations to secondary ends. Now what on earth does that mean?

An example: Let us imagine a proposal to test a cancer drug on humans. One of the ends here is the possible cure of cancer - an obviously good end. The testing will be done using control groups - an accepted means. Not enough volunteers are found to fill the control groups, so it is proposed that some cancer patients be given the new drug without their knowledge - unacceptable means. The process should stop there because individuals have rights and they must be protected. Thus the primary end, the protection of basic human rights, overrides the laudable secondary end of a possible cure for cancer, given the example of the unacceptable means of experimenting with human life without the consent of those involved.

However, let us suppose that arguments are made (by an ethics committee) that the benefits to humanity of the new drug are so great, that the unacceptable means can be tolerated, a lesser to two evils. A classic case of the end justifying the means, and a secondary end at that. This could also be justified under the "utilitarian ethic" principle of the greatest good for the greatest number.

In this case, it could be argued that the cure of cancer is actually a secondary end and certainly a good one, however, the primary or universal end involves the question of the effects on the human community, beyond the cure for cancer. In other words, is it in the best interests of a healthy, free human community to have life and death decisions about the health and safety of individuals being made by committees of researchers, with laudable, but secondary scientific ends? What about the larger issue of the rights of individuals in a free society? Researchers may free us from cancer, but who will free us from the researchers? The examination of primary ends must be made within a wider context than the scientific community. This is the problem of the ends (which ends), the ethical debate (whose ethics) and the debaters (experts, laymen, etc.).

Ethics in General - Ethics Defined

Ethics is about moral choices. Technically, ethics is the philosophical study of moral choices, thus it is often used interchangeably with the word morality. Ethics focuses on the rational investigation of the nature of "the good" and the process of making moral choices to achieve those goods that will enhance the well-being of human individuals, the entire human community and the world which they inhabit. In the human arena, the reference criterion for making moral choices is sometimes referred to as "authentic humanity". This is the primary or universal end.

For our purposes, the term “authentic humanity” attempts to express an ideal of human fulfillment: when an individual is in right relationship with self, others and the world. For the Greeks this was the notion of happiness or flourishing (*eudaimonia*), for the Hebrews this was a state of peace (*shalom*). Given this context, those human acts that enhance authentic humanity are judged to be moral (good) and those that diminish authentic humanity are judged to be immoral (evil). Therefore, ethics must address all areas of human life -- war and peace, economics and politics, love and marriage, government and business and a host of other areas. In a word, ethics is about life.

A Case for Bioethical Concern: Genetic Engineering

Human Genetic Engineering (HGE) research has identified four potential levels of application in humans:

1) Somatic cell gene therapy - the end here is therapy, curing a patient of some affliction by correcting defects in the somatic (bodily) cells of an individual. The means include genetic manipulation or genetic engineering. The universal ends of the promotion of authentic humanity and the means which protect the rights of individuals seem to indicate that this therapy is ethically permitted.

Successful therapy has been problematic, because it is difficult to change enough cells in a fully grown body to change bodily function enough to effect cure.

2) Germ line gene therapy - the end here is again therapy. However, “germ line” refers to a series of cells that eventually produce gametes - cells necessary for reproduction. Thus in manipulating germ line genes, not only is the disorder corrected in the patient, but this same disorder is also corrected in his or her offspring. Thus a new ethical dimension is added, the potential gene manipulation of individuals who do not yet exist.

Success of this therapy in future generations is judged to be easier to accomplish than somatic gene therapy, because only the one fertilized egg cell would need to be changed, and as it multiplied, the changes would be expressed in every cell of the person’s body, including the reproductive cell, and would be again passed on to the next generation.

3) Enhancement genetic engineering - the end here has shifted from therapy - cure of an illness - to the end of the enhancement of a non-disease characteristic such as height.

This type of HGE involves a wide variety of ethical issues, including who will determine what is proper “enhancement” and can we dictate some ideal “model” on future generation without their consent. Highly theoretical at this point in time, but probably possible in the future.

4) Eugenic genetic engineering - again this goes beyond therapy. It is an attempt to genetically alter or “improve” a series of complex human traits -- personality, intelligence, temperament, character etc.. This amounts to “designer” human beings.

Eugenics (the word means “well born”) was coined by Francis Galton a cousin of Charles Darwin. Inspired by Darwin’s theory of natural selection, Galton concluded that heredity and achievement were clearly linked. For some, this meant that if the achievement levels of the human race were to be protected and enhanced, those individuals who evidenced severely low achievement levels should not be allowed to reproduce. The eugenic madness of Hitler comes to mind, however we in the United States also have a sad chapter in “eugenic history”.

In 1927, in the case of *Buck vs Bell*, the U.S. Supreme Court affirmed the right of the state of Virginia to sterilize Carrie Buck against her expressed wishes. Carrie Buck was described as feeble-minded and the child of a feeble-minded mother. She had already produced an illegitimate child. Writing in a 8-1 decision Justice Oliver Wendell Holmes said:

It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.

The Justices never laid eyes on Carrie and the doctor on whose testimony they relied had never met her either. They did not consider relevant that the symptoms of her supposed imbecility may have been a psychological withdrawal due to the fact that she had been abandoned by her mother at the age of four, had been raped and impregnated by a friend of her foster parents and had been sent away to have her baby in a mental institution to avoid public scandal.

In 1979 the director of the hospital in which Carrie Buck had been sterilized searched her out. He testified that it was abundantly clear that neither Carrie, nor her sister who had also been forcibly sterilized, were in fact feeble-minded or imbecilic. And Carrie’s baby - Justice Holmes’s third generation imbecile - had been a child of normal intelligence.

Framing the Debate: The Problem of Ends

Earlier ethical debates had often placed authentic humanity and its protection as the ultimate end against which to test all means and secondary ends. For example, forced sterilization of those deemed to be “unfit” was judged to violate individual human rights (an attack against authentic humanity) even granting that sterilization procedures were medically safe and even granting, *for the sake of argument*, that the “unfit” may produce others who were unfit. These secondary ends of protecting the world from those judged “unfit” had to yield to the primary or ultimate goal of protecting individual human dignity.

However, much the same thing has been occurring in the current bioethical debates. Bioethical committees, composed mainly of scientists, have concentrated on secondary ends, i.e., will expected benefits occur (secondary ends) and are the procedures safe

(means).

Why are the primary or ultimate ends being neglected? There is no clear answer, but there may be a hint in the title of a 1963 conference of biologists and eugenicists. It was titled *The Control of Human Heredity and Evolution*. Perhaps the premise here was that evolution and its drive toward the survival of the fittest was now being taken over by the human mind. We are now in control and ought to be in control of our own destinies. Not only that, but the scientists, not the general public are those qualified to be in charge.

In this scenario there is no established primary or universal end - authentic humanity - against which to judge the ethical propriety of scientific endeavors. Authentic humanity is what we make it to be.

Of course, this is too simple an answer, but it is an answer with some truth about it. The truth of this lies in the fact that the general public along with philosophers and theologians are being gradually excluded from the decision making in the area of HGE.

How to Proceed from Here

Whatever the final bioethical conclusions about HGE and other bio-technical efforts, the debate needs to be broadened in two ways. First, the number and kind of participants needs to expand to include other ethical stakeholders, including in some way the general public. Secondly, at least the idea of the primary and universal end of authentic humanity must be reintroduced into the debate.

Is there, in fact, an authentic humanity toward which we all strive that can be ethically violated and thus at times must be protected? Or is our authentic humanity yet to be designed and implemented? If the historically inadequate short term goals regarding Carrie Buck and their surgically “safe” means of achieving them seem grotesque and wrong to us now, in light of Carrie’s human rights, what about our present secondary goals? How can we avoid our own historically conditioned catastrophe?

One Final Problem

One of the primary reasons that public ethical debate is so limited in this country is because we live in an ethically pluralistic society and thus we have difficulty in establishing common ground for ethical discussion. Because of our religious diversity, ethical norms based solely on our religious heritage cannot provide the common ground for ethical discussion.

However, there is an ancient ethical system which can provide this common ground in a pluralistic society and that is natural law. Natural law is based on human reason - which we share in common - and human nature - which we also share in common. Therefore, natural law is understood as knowable to the unassisted human mind, that is, to the human mind which does not reference divine revelation as its source of moral wisdom.

Natural law theory is based on the presumption that human nature is in some sense normative for human action. Those committed to a natural law tradition assume that reasonable people can discover together what it means to be human and what ethical principles need to be adopted and what civil laws need to be enacted in society so that human life can flourish.

A Final Word

In any event, there are a multitude of ethical challenges ahead, especially in the area of bioethics. The possibilities are exciting and perhaps we are on the brink of new medical breakthroughs. We certainly do not want to destroy scientific progress by blindly rejecting what is new and possible, at the same time we do not want to destroy our authentic humanity by blindly accepting anything, just because it is new and possible.