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The Ethical Concerns of Parental Eugenics and Gene Therapy

Introduction

A phenomenon so primal and rooted in every existing species is that of reproduction. At this juncture of the twenty-first century, the human race has made great strides in developing technology to enhance or alter this very basic process of creating new life. More sophisticated methods of reproduction necessitate the evaluation of the ethical and moral implications. With technology of genetic testing, scientists can identify and isolate genes of a person in vitro and speculate on the impact these genes will have on the individual's life. However, what portion of a person's life is dependent upon his or her genetic "instructions?" Who has the responsibility of "choosing" these genes for an unborn person? These issues are just some of the difficult questions comprising the category of Parental Eugenics and Gene Therapy. Scientific procedures which prompt these ethical dilemmas include: the selection of fetal sex; positive somatic cells and germ-line genetic therapy; and negative somatic cells and germ-line genetic therapy. It is inevitable that reality will go beyond the realm of science fiction. Philosophical books and medical ethical journals have explored the vexing questions of morality in advancing gene therapy technology. New biological knowledge demands that people learn how to behave in a society

filled with radical possibilities. Afterall, the problem is not technical—it's social.¹ Science will surely forge ahead, but the question is whether society will be able to handle the power of such technology.

Sex Selection

There are many old wives tales on how to predict the gender of an unborn child. These myths indicate the centuries old goal of having control over the sex of a baby. The folk measures which prescribe certain timing in sexual intercourse or a mother's diet are crude and laughable in comparison to today's technical understanding. Although there are some rare exceptions to the general rule, the human ovum (containing 23 chromosomes including the X chromosome) is fertilized by a spermatozoon (containing 23 chromosomes including either an X or Y chromosome) to produce an embryo with 46 chromosomes in either a male (XY) or female (XX). Sex selection is achieved through the scientific separation of X-bearing and Y-bearing sperm for fertilization of the ovum. In 1973, the journal *Nature* published two reports which showed the first time that X and Y-bearing sperm could be preferentially separated or destroyed on the basis of the chromosomes' different weight, the presence of a marker which fluoresces in the Y sperm, or by the occurrence of substances on the Y sperm surface capable of eliciting an immune response (Lappé, 1).

To blindly indulge in this technology for gender preferences would prove foolish. Many possible implications of sex selections are perilously unknown. Science has proved that it is impossible to discretely alter one event without causing a chain effect on succeeding generations.

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One school of thought is that outright choosing the sex of one's child will reduce the number of individuals who would otherwise be abused and neglected, and thus reduce birth rates. This argument addresses certain cultural beliefs which include favoring a certain sex to carry on the ancestry line, the desire for a strong worker, or even the hope that a certain gender would allow a child to have an easier time in society. A child who does not meet parental gender expectations may be subject to neglect and general dissatisfaction. However the fear remains, that regardless of expected results, mistakes may occur and the "undesired" sex may be born. In this case, how would the child's life be affected? In a time when politically correct ideals regarding androgyny is increasing, the technology of sex selection might actually be a step backwards. Sex selection lends itself to the stereotyping of sex roles. Tolerance towards different gender roles would therefore be jeopardized. "The psychological problems implicit in homosexuality and lesbianism might well be exacerbated as society's ability to accept gradations of sexual identity shifts with the ability to effect 'pure' sex types" (Lappé, 2). With the promise of sex selection, gender roles will be subject to even more critical scrutiny. Parents who are so determined, both psychologically and financially, to have a child of a particular gender may be less flexible with their child's sex role preferences than would parents who chose to have their child "the old fashioned way."

A type of cultural or financial discrimination also enters the parental eugenics equation. Selecting for children with certain preferred genomes may be dictated by cultural status or religious beliefs. Only parents with the financial means or religious freedoms would be able to empower their children with such genetic consideration. The consequences of this a genetic advantage—real or perceived—may have greater implications than the difference in environments caused by the wealth, class or beliefs of a child's family. "It would be an extension of those kinds of advantages, with possible implications for class structure and distributive justice" (Greely, 480). We are unsure of the magnitude of difference between children with a pre-established genetic advantage versus children with few resources and poor living environments.

There are critics who argue that sex selection is not a good way of reducing birth rates. They claim that there are alternatives to achieving better family planning than implementing such drastic genetic measures. In many third world countries, high birth rates are indicative of a women's poor status or low-level of education. Women have children to increase the number of workers on the family's land or simply because they do not have the resources or knowledge of contraception. Birth rates decrease markedly when the status of females is improved (Young, 582). Thus, opponents to sex selection promote their "ethical path" to population control—affording more educational opportunities and work to increase the status of women.

Regardless of motivation for sex selection, the wide use of the procedure may appreciably disturb the existing sex ratio. How would this affect the "gender equality" movement? If males were preferred and genetically "chosen" more often than females, would this reinforce the superiority of men? Or would this make women a scarcity and thus more valuable? There is already a preponderance of males at birth (51.6%), but that is compensated by a higher male mortality rate throughout life (Lappé, 1). The utilization of sex selection may very possibly unbalance this delicate sex ratio. There is the assumption that if one sex is selected more often, another aspect of life adjusts to return the proportions to the original equilibrium. This kind of self-adjusting, biological laissez faire approach may not be entirely possible. "Once we exert *artificial selection* for one sperm type over another, it is entirely possible that we will have

selected for sperm which carry the genetic potential for producing some offspring whose own gametes (be they sperm or eggs) would again have a predilection of the same sex" (Lappé, 2). Distortions in the balance of sex ratios in insects have been shown to be partly due to heritable mechanisms. Human manipulation can possibly throw our population's sex ratio into a flux, causing a self-perpetuating preponderance of one gender over another.

Somatic and Germ-line Gene Therapy

To further blur the distinctions of moral and ethical implications of genetic therapy, there are different categories within scientific manipulation. Gene therapy on somatic cells result in changes which effect only the specific individual. Treatment targeting germ cells or on preembryos, produce results which will infiltrate the generations and be inherited by future offspring. Further distinctions include the use of positive and negative gene therapy. Although the differences between these specifications are not clearly defined, they roughly refer to the therapy on an individual with the aim of improving the organism (positive) or therapy whose endeavor is to repair damage or cure some disease (negative). These distinctions are very subjective and can be taken in different contexts. A therapy is considered as " 'negative' in relation to some kind of norm, which the organism does not satisfy, unless [the organism is] subjected to the therapy in question" (Tannsjo, 232). The following are four different contexts of gene therapy in order of increasing societal anxiety—from the most socially acceptable therapy to the most controversial and ambiguous manipulation of genetic material.

Negative Gene Therapy on Somatic Cells

This type of gene therapy seems to be the most widely accepted. There is a consensus that fixing the genetic material in somatic cells, without passing on the changes to the next generation and with the goal of curing an existing disease, is beneficial and a positive result of technological advancement. Even the Pope has endorsed these views; although there has not been an overwhelming utilization of this therapy, scientists are optimistic and "there should be no special moral problems in this area" (Tannsjo, 232).

Positive Gene Therapy on Somatic Cells

Positive Gene Therapy on Somatic Cells can be considered the "cosmetic" or "plastic surgery" of gene therapy. Take for example the case of sight correction. If the current practice of corrective eye surgery is approved and accepted, gene therapy to achieve the same means should be equally welcomed. Although less than perfect vision is not a disease per se, it is a handicap which may be ameliorated through gene therapy. However, we must look at the extremes of the situation. This type of gene therapy may have a movie-star vanity stigma, and may not be high on the priority list for urgent medical technology. It will nevertheless be an appealing choice for dissatisfied people. To these means, what kind of regulation would we put on the enhancement of certain characteristics? Will we become a race of superpeople—8 feet tall pro-basketball players, capable of hearing a cotton ball drop on a carpet floor a mile away? We are a society which prides itself in self-improvement and striving for the best. Eventually, however, there will have to be a practical limit to our progress. Who will be the "genetic police" and how will limits be established? Endeavors which initially seem innocuous may unknowingly open Pandora's box.

Negative Gene Therapy on Germ-Line Cells

Since gene therapy on germ-line cells would most often involve the manipulation of a preembryo, the case may be able to fit under the category of genetic testing and in vitro fertilization selection. If it is identified that there are genetic defects in a certain pre-embryo, it may simply be easier to destroy it and use another fertilized egg which is free of such malformations. This scenario is plausible barring anti-abortionist and other moral opposition to just "throwing away" a pre-embryo. However, germ-line therapy may be most efficacious when dealing with disease. In his article, Torbjorn Tannsjo proposes a hypothetical situation of some very ravenous and infectious disease to which some have natural resistance. Would not all parents want their children to have this immunity? To extend the analogy, children already have mandatory vaccinations such that they will be immune to certain diseases. How different would it be for children to have those vaccinations in vitro? And then, how much more questionable would it be for germ-line genetic therapy to give all children henceforth an automatic genetic vaccination? This exposes an ambiguity in the whole concept of negative gene therapy on germ-line cells. If the idea is to *fix* a disease or condition, and performing this therapy on germ-line cells causes the change to be perpetuated for all generations, then there will be no disease to cure anymore. Nevertheless, until this type of gene therapy is incorporated into medical procedures at large, negative gene therapy on germ-line cells will continue to be an issue for moral and ethical debate.

Positive Gene Therapy on Germ-line Cells

Treatment of germ-line cells alludes to the Nazi spectre when dealing with positive eugenics and gene manipulation to "enhance" human characteristics. Due to the nature of germline gene therapy, manipulated genes stay in human society to be passed on to successive generations after the individual has been treated. Thus it is the rights of the unborn child which must be considered. Because of the self-perpetuating nature of germ-line cell therapy, even greater consideration must be afforded to this type of genetic manipulation. If any mistakes are made or second-thoughts on the genetic alteration occur, the situation may already be out of the hands of the scientist. With humans having multiple offspring, the gene would propagate exponentially through generations. On the flip side, if positive gene therapy on germ-line cells is not complete (i.e. not every single person in society is treated) the altered gene is subject to the same natural selection process as is any other "regular" gene in the human genome. If either positive or negative germ-line therapy was not performed on every individual of an entire population, the effects would eventually be "diluted" with those traits from untreated genes. Thus, certain feasibility measures and realistic costs of treating everyone may prohibit the true germ-line cell genetic therapy. The fear of irrevocably altering the human race may never come to past.

Conclusion

In all this debate of whether or not people should be allowed to manipulate genetics, the question looms: should we be allowed to play God? A Commission for the President of the United States writes, "all human activities, including gene splicing, proceed according to the scientific laws that describe natural processes" (Tannsjo, 239). Thus, human can rest assured

that most likely all our activities, as scientifically radical as they may seem, will always be dictated by the natural laws as established by whoever, or whatever created our living system in the first place. No inherent laws of nature are broken; rather skepticism and doubt toward scientific processes have been dispelled.

With such emphasis placed on screening an unborn child for genetic defects, the issue remains of how much genes actually matter? In the case of severe genetic diseases, such as Cystic Fibrosis or Huntington's Disease, statistics tell the story. However, for less discrete conditions such as less than perfect pitch and flat feet, how much of a person's happiness can genes dictate? The Nature versus Nurture debate arises once again. Afterall, if genes totally controlled who we are, then identical twins would be identical people—which is not true.

As parental eugenics through gene therapy becomes integrated into societal life, will we all be forced to genetically screen our children? Similar to the medical attention that we give children today, will gene therapy be an obvious treatment for disease? A parent may be considered irresponsible or neglectful if they knowingly bear a genetically defective child or fail to give the child appropriate gene therapy for his or her condition. However, how can we ever guarantee that a child will be born with a sound mind and body? The plan of detecting *all* genetic conditions *in utero* is just biologically unrealistic (Twiss, 10). If a society becomes so motivated to achieve genetic "perfection" and thus idealized expression of those genes, how can anyone safeguard a child from later becoming "damaged" in an accident? How will our society cope with a perfect phenotype of a person which has since become mangled in the course of living?

References:

- Greely, Henry T. "Legal, Ethical and Social Issues In Human Genome Research." *Annu. Rev. Antrhopol.* 1998;473-502.
- Howell JD. "The history of eugenics and the future of gene therapy." *J Clinical Ethics* 1991; 2:274-7.
- Lappé, Marc and Peter Steinfels. "Choosing the Sex of Our Children." *The Hastings Center Report* 1974 Feb; 4(1);9-11.
- Mamdani M. *The Myth of Population Control: Family, Caste and Class in an Indian Village,* 173pp. New York: Monthly Review Press.
- Stein, Jane J., *Making Medical Choices Who is Responsible?* Boston: Houghton Mifflin Company, 1978.
- Tannsjo, Torbjorn. "Should we change the human genome?" *Theoretical Medicine* 1993 Sep; 14(3):231-247.
- Twiss, Sumner B. Jr. "Parental Responsibility for Genetic Health." *The Hastings Center Report*, 1974 Feb;4(1);9-11.
- Young, Robert. "The ethics of selecting for fetal sex." *Bailliere's Clinical Obstetrics and Gynaecology* 1991 Sept;5:1