Ethical Implications of Germ Line Genetic Engineering

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Following the recent decision by the Obama administration to lift strict limitations on embryonic stem cell research, genetic engineering has once again come to the forefront of scientific discussion. An upcoming FDA-approved trial using human embryonic stem cells in recently paralyzed individuals has further prompted an analysis of the legal and ethical issues surrounding the use of germ line genetic engineering. Though prohibited globally due to inadequate safety and effectiveness, it is inevitable that these concerns will one-day be met by continual technological advancements. Nevertheless, there remains a plethora of issues such as equal accessibility for all socioeconomic groups, autonomy of descendents, and effect on the human gene pool to name a few. In this discussion, it is important to make the distinction between germ line genetic engineering used for therapeutic purposes (altering DNA to correct a genetic defect before it manifests itself as a disease) and enhancement purposes (altering DNA to improve an individual above “normal” functioning). Although the use of this technology could be justified for therapeutic purposes, it is very difficult, if not impossible, to morally defend interventions for enhancement purposes.

Introduction

Genetic engineering has once again come to the forefront of scientific discussion following President Obama’s recent decision to lift strict limitations on human embryonic stem cell research set by the previous administration in America. Coinciding with this was the approval of a phase I stem cell trial by the Food & Drug Administration aimed primarily at testing the safety of this therapy in eight to ten completely paralyzed patients with severe spinal injuries. The stem cells, which were obtained from embryos that would have otherwise been discarded, will also be used to test for any signs of functional recovery in these patients.

A lot of controversy has surrounded alterations made specifically in the germ line (sperm or egg), since they affect every cell in the child and would be transmitted to all future descendants. It is important to make the distinction between germ line genetic engineering used for therapeutic purposes (altering DNA to correct a genetic defect before it manifests itself as a disease) and enhancement purposes (altering DNA to improve an individual above “normal” average functioning).

Currently, many laws around the world prohibit the use of germ line genetic engineering due to safety concerns and the possible implications for future generations. In addition, the four principles of bioethics – beneficence, non-maleficence, autonomy, and justice – influence the debate regarding the future use of this technology. This article evaluates some relevant legal and ethical arguments that are important in determining whether germ line genetic engineering should be utilized in humans in the future.

Current Legislation

There are well defined Canadian and international laws governing the use of germ line genetic engineering. Canada’s Assisted Human Reproduction Act (2004) prohibits the alteration of “the genome of a cell of a human being or in vitro embryo such that the alteration is capable of being transmitted to descendants.” The prohibition is largely due to the questionable
nature of the safety, effectiveness, appropriateness and efficiency of the technology.\textsuperscript{5} This view is shared internationally,\textsuperscript{6, 7} and thus there are currently no legal cases pertaining to this topic around the world.

While the law dictates what can and cannot be done, the technology’s controversial nature makes it necessary to assess the many ethical issues involved. Laws often reflect changing societal values, and therefore are constantly evolving. As a result, ethical analysis becomes invaluable for future policy development.

**The Costs and Benefits of Germ Line Genetic Engineering**

The principles of beneficence and non-maleficence constitute the backbone of bioethics.\textsuperscript{8, 9} Beneficence asserts that there is an obligation to treat and improve the condition of others when it is possible to do so. Hence, altering the genome for therapeutic purposes on a permanent and heritable basis to prevent future genetic diseases becomes an obligation. This suggests that even within our limited capabilities, it is our duty to prevent any unnecessary harm and suffering and to improve the quality of life for future generations. The promise of enhancement to increase human functioning to above normal levels may seem very alluring and advantageous. Potentially favourable outcomes include a dramatic increase in life expectancy, a delay in the natural aging process, and increased tolerance and functioning of our immune system.\textsuperscript{10, 11} It is also fair to argue in favour of enhancements that improve health and mental acuity in general. Such enhancements will increase survivorship, quality of life as well as the life expectancy for future generations.\textsuperscript{12}

Nevertheless, the majority of techniques involved in this technology are in their early testing stages. This imposes numerous technical barriers that jeopardize the effectiveness and safety of such procedures, hence challenging the principle of non-maleficence; this principle states that a therapy should have a net benefit, loosely translating to “do no harm”.\textsuperscript{9} Additionally, germ line genetic engineering experiments involving animal models are highly inefficient and produce greatly variable offspring. The process requires breeding to be repeated through several generations until it results in a stable and permanent animal line with the desired properties. Not only would this be highly dangerous in humans, but because of the threat this presents to human dignity, it would also be impossible to justify morally.\textsuperscript{10} Insertion or modification of certain genes may also have unknown and potentially harmful interactions with other genes in the recipient genome. Similarly, the removal of disease-linked genes may remove the beneficial effects of those genes.\textsuperscript{10} Due to the unpredictable and largely unknown hazards of such procedures in humans, taking such risks is difficult to justify despite the potential benefits.

**Respecting the Right to Self-Governance**

Autonomy is the right to self-determination, which embodies freedom and the ability to determine one’s own future.\textsuperscript{10} In germ line genetic engineering, one must consider autonomy of the parent, the child, and his or her progeny. According to the principle of reproductive autonomy, parents have the right to use whatever therapeutic means available to ensure that they have a normal pregnancy and a healthy baby. However, this principle excludes the parents’ attempts to enhance the traits of their genetically normal offspring. Similar to situations where parental autonomy can be taken away in cases of social concern (such as child neglect), the American Association for the Advancement of Science has argued that strict legislation should regulate and differentiate between germ line genetic engineering for therapeutic versus enhancement applications.\textsuperscript{10}

The autonomy of the child and subsequent progeny must also be considered. Upon reaching adulthood, a child is considered a rational agent and it is therefore safe to assume that he or she would consent to most genetic augmentations.\textsuperscript{13} While this argument may apply for therapeutic purposes, autonomy for enhancement ordeals is more complicated. Traits that a parent may choose to improve (such as improved
mathematical versus physical abilities) may not be what the child or their progeny would have chosen to enhance if given the choice as rational adults. In such instances, issues of informed consent and violation of autonomy arise, leading to the possibility of legal cases that challenge the reproductive autonomy of the parents versus the autonomy of the child.

The Role of Justice

Justice is another fundamental ethical concept and requires that harms and benefits be distributed equally among the whole population. If certain procedures become classified as therapeutic, it is reasonable for individuals to ask that such services be made universally available. It can be argued that germ line therapy is analogous to largely accessible public health initiatives aimed at preventing heart disease and therefore should also be accessible to the majority of the population. Nevertheless, even if therapeutic germ line genetic engineering becomes covered under a universal health plan, such as Medicare in Canada, long waiting lists will likely pose a myriad of problems.

On the other hand, the prospect of germ line genetic engineering for enhancement purposes becoming covered under public health insurance is highly unlikely. Thus, the wealthy would have greater access to this technology, further expanding the divide between different socioeconomic groups in society. This skewed access raises a few critical concerns. Those unable to afford this procedure would likely have some undesirable traits and could be viewed as abnormal. In contrast, those able to afford it would have greater control over shaping the human gene pool by removing undesirable traits while enhancing beneficial ones, leading to a form of eugenics within society. Additionally, alterations in the germ line would be carried on throughout the progeny of an individual, maintaining this inequality throughout future generations.

Conclusions

As we venture into the twenty-first century, technological advancements continue to expand the horizons of human potential, while also raising important ethical issues; germ line genetic engineering is one such advancement. Although these procedures are legally prohibited due to their lack of safety and effectiveness, it is important to develop an understanding of the implications on society to help make more informed decisions about their future uses. Though by no means exhaustive, this paper aimed to analyze and discuss the four major principles of bioethics - beneficence, non-maleficence, autonomy, and justice - as related to germ line genetic engineering. Through this analysis, it seems that though the use of this technology could be justified for therapeutic purposes, it is very difficult, if not impossible to defend morally for enhancement purposes.

Among other concerns, the availability of this therapy to the public would require extremely close monitoring of its health effects (harms and benefits in both the short and long term), as well as ensuring equal access for everyone in a timely manner regardless of their socioeconomic status. Failure to do so could result in deleterious situations from dire health effects for patients and their progeny to discrimination based on ones genetic make-up. Though there are endless possibilities in improving both the quality and quantity of human life, it is critical to ensure that genetic engineering is safe, effective, reasonable for future generations, and equally accessible before it can become a viable component of both the scientific and global community.

References


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