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Human Germline Engineering

Bailey Affolter

San Jose State University

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I. Introduction

Scientific advancements in understanding and manipulating the human genome have given way to research development in the field of human germline modification. This involves splicing DNA in a process commonly referred to as CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats), which is the injection of materials that target and alter certain defective genomic sequences in gametes, or embryonic cells¹.

Experimentation has been carried out on embryonic cells, and this practice is not yet offered in a clinical setting to parents seeking to eliminate the chance of disease for their progeny, though that is the intention. Germline modification affects future generations as well, as it results in harmful alleles/genes being eliminated from the gene pool.

I feel that it is appropriate for such alterations to take place under heavy restrictions, always with consideration of the child's quality of life, existing cultural values and systems that may take interest in the preservation of certain genotypic/phenotypic traits, and political, medical, and social ramifications for future generations. A panel of the National Academy of Sciences identified that germline modification is not appropriate for enhancements like intelligence "at this time"². I would argue that this time should never come, to promote equitability and genetic diversity within society. It is imperative that policy-makers, healthcare professionals and individuals proceed with caution, so as not to engage in policies or practices that echo norms of the eugenics era. For this reason, human germline engineering should be limited to treating/eliminating diseases that cause prolonged suffering, either immediate or delayed, in a progressive, degenerative manner, and that are likely terminal, or life-threatening. Some examples, for the sake of elucidation, are cystic fibrosis, muscular dystrophy, Tay-Sachs,

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or inherited cardiac arrhythmia, to name a few, though the US panel purposely did not make a list of acceptable diseases³.

II. Ethical Perspectives and Values

Principlism

The first ethical perspective that I will use to address the issues of human germline modification are that of principlism, using values such as autonomy and justice. If this treatment were to be offered in a clinical setting, the autonomy of the patients ought to be respected. The choice to opt-in to this procedure is a right that if offered, should be made equitable in its accessibility. This includes the rights of a patient not to be compromised if they possess a certain disease and they choose not to undergo this type of gene therapy for their offspring. Though in the United States there exist laws such as HIPAA that protect patient information, these protections could easily be reduced if the government thought it in their best interest to promote the coverage of this procedure, and discourage the presence of diseases in society. Those possessing genotypic, or even phenotypic markers of disease might be implicated if they fail to report it. Increasingly, insurance companies in the United States might exert their influence over policy to move back toward a model that refuses to offer coverage to those with pre-existing conditions. This is an issue of distributive justice. Additionally, it is an issue of social justice. If progress and successes in this area of research were to continue, medical and social norms could become such that those free of disease would be regarded with greater value in society than those with a disorder or condition. The individual with a disease may themselves be considered a blight or burden on society, and thus experience differential treatment within that society. This again threatens their autonomy, as their status in society would decrease along with their

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perceived level of social empowerment. This is a liberty that ought to be extended to everyone on an equal basis.

UDBHR

The universal declaration of bioethics and human rights is useful in addressing dilemmas that are meant to transcend temporal or geographical/national constraints, in order to establish consensus on equal treatment for all on the basis of our shared humanity.

One very pertinent statute of the UDBHR that I wish to address first is respect for cultural diversity. It is important to note that cultural diversity and pluralism does not always refer simply to culture in the ethnic/geographic/national sense. It can also connote cultures formed by individuals whom collectively experience certain kinds of disabilities. In a Newsweek article, author G. Burningham points out that it is crucial to consider certain populations like the deaf population⁴. There exists a whole language and culture for these people. It is common for them to take part in fulfilling lives, and to thrive within many areas of society. To eliminate their culture would be to ignore their value to society. This argument also serves the value of non-discrimination and stigmatization with respect to dignity and rights. As we look back on the principle of autonomy, it is the responsibility of governments, health professionals, and individuals within society to respect the rights of diverse groups, and not to impede their freedoms. Perhaps with the steady elimination of deaf people, those still alive to witness this transition would experience discrimination, either through active social norms, or lack of available resources, as people phase out of providing for this sector of society. The same would go for other heritable cases like blindness. Those whom experience an accident that results in such a handicap will also share these difficulties.

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Care perspective

I feel it is appropriate now to employ the care perspective in this discussion, as a way to integrate these values in practical manner within the clinical setting. The professional codes of ethics for doctors and nurses establish obligations to the law, to public health and equal access, to prioritization of patients and their privacy, and to the universality of human rights. One cannot balance all these obligations without proper moral understanding and awareness of the relationships and needs of the patients during the process of consultation or provision of this procedure. The professional must be extremely lucid of: the morality of social norms, which may influence a patient's decision; the law which may or may not empower certain people to receive such a procedure; the ability of a family to care for a child if they were to be born with a specific condition. They have to consider the desires of the family, and determine whether the parents have made the decision to seek out this procedure with their own best interests, and best interests of the child in mind, or whether it is being done for selfish or unethical reasons, whatever that may be. A morally mature physician would have to use their faculties of compassion and empathy to promote this procedure if it is reasonably of benefit to all parties involved, because the ultimate intention should be to use current technological advancement for the sake of alleviating the harm that one may experience if they are brought into the world with such a disease. If a physician or nurse has an ideology that does not endorse tampering with genetic information, it is here that they must consider the utilitarian good versus bad for their patient, and act accordingly. They still have to ability to refuse treatment, but they must not bar a couple or individual from seeking out this procedure if it is reasonable for them to ask, especially if informed consent of the patient has been obtained and moral awareness is maximal.

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Law

The “Common Rule” law, based on the Belmont Report that exists concerning human research subjects can also be applied here. The principle of respect for persons really is only applied to the parents of the child, in that they must receive informed consent of the possible risks of the procedure, which include somatic mosaicism, which is a case in which an individual is born with two sets of genetics, essentially. The risks associated with this are an increased risk for cancer through mutations, or neurodegenerative problems. This issue has been dramatically reduced in recent times, however, along with other unintended effects of the CRISPR procedure⁵. This is also a factor of the beneficence principle. To do no harm, but to also be of benefit to the patient and to society as a whole means that these side effects would be eradicated, and that the life threatening disease would be completely eradicated without other considerable defects/ damage to the embryo’s DNA upon implantation. Additionally, researchers and developers of this procedure have to be cognizant of the fact that allowing DNA enhancements along with eradication of disease would be a potential issue for the child that is born with designed traits. Parents whom would go beyond seeking gene therapy for a harmful disease, and want to select the attributes of their child might be more likely to use the child for their own ends, or view the child as a pet, instead of an autonomous individual. Researchers and health professionals alike must not allow such a practice to take place. The principles of beneficence and justice come into play, because researchers have to be aware of the current prejudices that certain members face in society, and not enable a social climate that continues to favor certain traits over others.

Objections

One could argue that autonomy of individuals qualifies a libertarian argument: if a service is available, people have the right to use it according to their values for what are desirable

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traits in a child. Additionally, it can be argued that the claims concerning distributive and social justice are unfounded because they are projections of the future conditions of an unrealized society. I find it useful however, to make such predictions in the event that history repeat itself. In the early 1900's was the concept of Social Darwinism, which favored certain traits over others, and justified economic and social domination of certain people over others. This gave way to the eugenics movement in the United States, which was a hush-hush policy and series of that programs that brought about sterilization of minorities, immigrants, disabled, and women deemed unfit to be mothers by the judgment of various physicians. The option to essentially design children according to common beauty standards is unethical in that it would surely propagate prevalence of certain traits, arguably along socio-economic boundaries. This practice would foster another dimension of classist inequity, which is a potential infringement on individual liberties and autonomy. One's expression of autonomy must not infringe upon another's. No individual's liberty has preference over another, ideologically speaking.

1 Connor, S. (2017, July 26). First human embryos edited in U.S., using CRISPR. Retrieved December 05, 2017, from <https://www.technologyreview.com/s/608350/first-human-embryos-edited-in-us/>

2 Regalado, A. (2017, February 14). U.S. panel endorses babies gene-edited with CRISPR. Retrieved September 20, 2017, from <https://www.technologyreview.com/s/603633/us-panel-endorses-designer-babies-to-avoid-serious-disease/>

3 Ibid.

4 Burningham, G. (2016, June 09). We're about to be able change what it means to be human by editing our DNA. Retrieved September 20, 2017, from <http://www.newsweek.com/human-genome-editing-crispr-454315>

5 Connor, S. (2017, July 26). First human embryos edited in U.S., using CRISPR. Retrieved December 05, 2017, from <https://www.technologyreview.com/s/608350/first-human-embryos-edited-in-us/>