THE ETHICS OF HERITABLE NON-THERAPEUTIC HUMAN GENOME EDITING

THE ETHICS OF HERITABLE NON-THERAPEUTIC HUMAN GENOME EDITING

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ABSTRACT

This thesis considers the moral permissibility of heritable non-therapeutic human genome editing. That is, genetic changes that seek to alter the genes of future generations for enhancement and aesthetic reasons. Some examples include genetic changes to muscle mass, cognitive abilities, eye colour, hair texture, skin colour, and so on. Given relevant moral considerations, I argue that the case against heritable non-therapeutic human genome editing is stronger than the case in favour.

GLOSSARY

(Hine, Robert. *A Dictionary of Biology*. Oxford University Press, 2019.)

CRISPR-Cas9	A technique for editing DNA in living cells that can block, repair, or modify specific genes. It is based on a system found in prokaryotes (both bacteria and archaea) that involves a genetic locus called CRISPR (clustered regularly interspaced short palindromic repeats) and CRISPR-associated protein 9 (Cas9).
epigenome	The sum of all the chemical modifications to DNA or chromatin that influence the activity of genes but do not affect the sequence of bases—i.e., changes that are literally 'above the genome'. These epigenetic tags play a key role in determining which genes are active or inactive in particular tissues, and they can be inherited by offspring.
DNA	The genetic material of most living organisms, which is a major constituent of the chromosomes within the cell nucleus and plays a central role in the determination of hereditary characteristics by controlling protein synthesis in cells. It is also found in chloroplasts and mitochondria. DNA is a nucleic acid composed of two chains of nucleotides in which the sugar is deoxyribose and the bases are adenine, cytosine, guanine, and thymine.
gene	A unit of heredity composed of DNA. In classical genetics a gene is visualized as a discrete particle, forming part of a chromosome, that determines a particular characteristic. It can exist in different forms called alleles, which determine which aspect of the characteristic is shown (e.g. tallness or shortness for the characteristic of height).
gene pool	All the genes and their different alleles that are present in a population of a particular species of organism.
gene therapy	The application of genetic engineering techniques to alter or replace defective genes. A defective gene may result from an incorrect sequence of bases in the DNA molecule or an inability of the gene to code for the expression of a particular polypeptide.
genome editing	Any of various techniques for making precise, site-specific changes in the base sequence of the DNA of an organism. Each uses an engineered DNA-binding construct to seek out the target sequence, and a nuclease enzyme to cut the two strands of the DNA double helix at the required site. By exploiting the cellular DNA repair mechanisms, small inserts or deletions can be made at a single site, often causing inactivation (knockout) of the affected gene. Further, by cutting at two sites, larger inversions or deletions can result; and when a donor DNA template or transgene is introduced with the editing module, entire genes can be corrected or replaced. Genome editing is performed chiefly for genetic research, but increasingly is seen as a valuable technique to correct harmful mutations during gene therapy, and to engineer transgenic organisms, especially in animal and plant breeding.

germ cell	Any cell in the series of cells (the germ line) that eventually produces gametes, especially the first cell in such a series. In mammals the germ cells are the oogonia (in the ovaries) and the spermatogonia (in the testes).
methylation	The addition of methyl groups to constituent bases of DNA. In both prokaryotes and eukaryotes certain bases of the DNA generally occur in a methylated form, and in eukaryotes it has a major role in epigenetic control of DNA transcription.
mosaic	An organism made up of cells that have different genotypes but have developed from the same zygote.
mutation	A sudden random change in the genetic material of a cell that potentially can cause it and all cells derived from it to differ in appearance or behaviour (i.e. in phenotype) from the normal type. An organism affected by a mutation (especially one with visible effects) is described as a mutant. Somatic mutations affect the nonreproductive cells and are therefore restricted to the tissues of a single organism. These can lead to diseases such as cancer. Germ-line mutations, which occur in the reproductive cells or their precursors, may be transmitted to the organism's descendants and cause abnormal development or early embryonic death.
protein	Any of a large group of organic compounds found in all living organisms. Proteins comprise carbon, hydrogen, oxygen, and nitrogen and most also contain sulphur; molecular weights range from 6 to several thousand kilodaltons (kDa). Protein molecules consist of one or several long chains (polypeptides) of amino acids linked via peptide bonds in a characteristic sequence.
RNA	A complex organic compound (a nucleic acid) in living cells that is concerned with protein synthesis. In some viruses, RNA is also the hereditary material. Most RNA is synthesized in the nucleus and then distributed to various parts of the cytoplasm. An RNA molecule consists of a long chain of nucleotides in which the sugar is ribose and the bases are adenine, cytosine, guanine, and uracil. Messenger RNA **(**mRNA**)** is responsible for carrying the genetic code transcribed from DNA to specialized sites within the cell (known as ribosomes), where the information is translated into protein composition).
somatic	Relating to all the cells of an animal or plant other than the reproductive cells. Thus a somatic mutation is one that is not heritable.
TALEN	Transcription activator-like effector nuclease. An engineered protein consisting of a nuclease enzyme and a DNA-binding module based on a family of proteins (transcription activator-like effectors) occurring naturally in bacteria of the genus *Xanthomonas*. They are used in genome editing to introduce changes to the DNA of cells at specific sites.
zinc finger	A structural motif characteristic of certain proteins that bind to DNA, notably transcription factors. It consists of a finger-like fold of amino acids at the base of which lie two cysteine and two histidine residues.

INTRODUCTION

There have been numerous technological breakthroughs throughout history that have inconceivably shaped our world, from the internet to antibiotics, to the semiconductors in our laptops and smartphones. This project considers a technology that has not had enough time to yield its transformative power yet remains on the cusp of something profound. It is found in recent advancements in genetic engineering that promise the revolutionary ability to alter human genes.

For most of history, the idea of genes functioning as the basic units of heredity was unknown. By the mid-nineteenth century, as Gregor Mendel, the father of genetics, was performing experiments, many thinkers held largely misguided views of heredity. For instance, Darwin held Pangenesis, a theory of inheritance that depended on "gemmules," or hereditary particles released from body cells that would eventually make their way into our gametes.[1]

When English botanist, William Bateson, discovered Mendel's work, especially his groundbreaking experiments on pea plants, he introduced and popularized the term *genetics* in 1905.[2] Subsequently, various discoveries were made in the field that have led to our contemporary understanding of genetics. One striking achievement was James Watson and Francis Crick's discovery of the double-helix structure of DNA in 1953, a discovery that was made possible by Rosalind Franklin's innovative work in X-ray diffraction.[3] This gave us significant insight into how DNA, or the code of life, is chemically constructed.

As our comprehension of genetics continued to evolve, particularly with the successful mapping of the human genome in 2003, scientists had developed two methods of gene editing.[4]

These were zinc-finger nucleases (ZFNs) and transcription activator-like effector nucleases (TALENs).[5] While these two approaches could alter DNA, they were quite time-consuming, imprecise, and expensive. The biggest milestone in gene editing came in 2012 when scientists Jennifer Doudna and Emmanuelle Charpentier discovered CRISPR-Cas9, a new and precise technology that can alter DNA.[6] This discovery eventually received the Nobel Prize in Chemistry and was considered to have "taken the life sciences into a new epoch."[7]

Often described as "genetic scissors," CRISPR-Cas9 possesses the ability to cut, insert, and replace sections of DNA.[8] In 2015, despite the concerns around safety and moral permissibility, scientists in China used CRISPR-Cas9 in *non-viable* embryos.[9] Junjiu Huang and colleagues attempted to modify the gene that causes Beta-thalassemia, a rare genetic blood disorder.[10] Even more controversially, in 2018 at the Second International Summit on Human Genome Editing, He Jiankui announced to the world he had created the first genetically modified babies with *viable* embryos.[11] This was highly unethical and as a result, Jiankui was condemned by the scientific community.

Jiankui's actions led to a global moratorium around heritable human genome editing.[12] He completely halted the progress made in the field. As a response, the World Health Organization (WHO) established the Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. This committee has recently declared gene editing to be too risky at present.[13] Altering human DNA with gene-editing technologies like CRISPR-Cas9 remains limited, both in science and law, at least until we determine how it should be governed.

What happens next will prove decisive in determining the path our world is headed with human gene editing. In this critical juncture, I hope this project can facilitate the reader to develop

their moral stance on the matter, and by so doing can spark a conversation around how this technology should be adopted (if at all). As will become clearer throughout the work, my particular focus is on a specific—yet contentious—type of human genome editing: heritable non-therapeutic human genome editing. That is, genetic changes that seek to alter the genes of future generations for enhancement and aesthetic reasons. Some examples include genetic changes to muscle mass, cognitive abilities, eye colour, hair texture, skin colour, and so on.

This work contains five chapters and can be summarized as follows. Chapter 1 sets the groundwork for the rest of the thesis by considering and revising the current framework used for moral deliberation regarding the permissibility of human genome editing. It broadly aims to introduce the reader to the human genome editing debate before taking any moral stances. I argue that while the current framework (making use of the treatment-enhancement and somatic-germline distinctions) is under attack, it is nonetheless feasible to use with some added revisions. This chapter is not intended to discard the current distinctions, but to widen them for accurate deliberation on the matter.

Chapter 2 considers some arguments in favour of heritable genetic *enhancements* (i.e., one of two forms of heritable non-therapeutic human genome editing). I consider two arguments by John Harris that provide a positive case for pursuing heritable genetic *enhancements*. I suggest that they do not amount to a moral obligation to pursue them, even if they can be identified as good things. Chapter 3 serves as a continuation to the previous chapter by considering some arguments against heritable genetic *enhancements*. Given the concerns around inaccessibility, I argue that because heritable genetic enhancements will likely yield significant harms and produce minimal good, we have moral reason not to pursue heritable genetic enhancements.

Chapter 4 moves onto heritable *aesthetic* genetic changes (i.e., the second form of heritable non-therapeutic human genome editing). In this chapter, I suggest that while aesthetic genetic changes can be characterized as neutral (because they do not make us better or worse), concerns around liberal eugenics and parental imposition give us moral reason (at least tentatively) not to pursue them. Chapter 5 considers a hypothetical case study of prospective parents who desire to bear a child with non-therapeutic genetic changes. This chapter is meant to collectively consider the possible good and negative outcomes that heritable non-therapeutic human genome editing can bring. I suggest that when we weigh the positives against the negatives, it becomes clear that we have little to gain and a lot to lose if we decide to pursue heritable non-therapeutic human genome editing. My cumulative argument in this thesis is as follows: given relevant moral considerations, the case against heritable non-therapeutic human genome editing is stronger than the case in favour.

Notes

[1] James Schwartz, *In Pursuit of the Gene: from Darwin to DNA* (Cambridge, MA: Harvard University Press, 2009), 2.

[2] A.M. Winchester, "Genetics," Encyclopedia Britannica, May 15, 2020, https://www.britannica.com/science/genetics.

[3] Ibid.

[4] Judith Fridovich-Keil, "Gene Editing," Encyclopedia Britannica, July 4, 2019, https://www.britannica.com/science/gene-editing.

[5] Ibid.

[6] A Cas-9 protein paired with messenger RNA.

[7] "The Nobel Prize in Chemistry 2020," NobelPrize.org, accessed July 31, 2021, https://www.nobelprize.org/prizes/chemistry/2020/summary/.

[8] Ibid.

[9] David Cyranoski and Sara Reardon, "Chinese Scientists Genetically Modify Human Embryos," *Nature*, 2015, https://doi.org/10.1038/nature.2015.17378.

[10] Ibid.

[11] David Cyranoski, "The CRISPR-Baby Scandal: What's next for Human Gene-Editing," *Nature* 566, no. 7745 (2019): pp. 440-442, https://doi.org/10.1038/d41586-019-00673-1.

[12] Eric S. Lander, et al., "Adopt a Moratorium on Heritable Genome Editing," *Nature* 567, no. 7747 (2019): pp. 165-168, https://doi.org/10.1038/d41586-019-00726-5.

[13] Gina Kolata, "W.H.O. Experts Seek Limits on Human Gene-Editing Experiments," The New York Times, July 12, 2021, https://www.nytimes.com/2021/07/12/science/gene-editing-crispr-who.html.

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1

A REVISED FRAMEWORK

1. Introduction

The urge for a global moratorium on heritable human genome editing intensified after the CRISPR-babies scandal with He Jiankui in 2018. This moratorium is set to last, at least, until a framework for governance is devised.[1] This interim period has been a time for moral deliberation about whether human genome editing is permissible. Numerous journal articles, ethics statements, international policy documents, and surveys have been published that decidedly take a moral stance on the permissibility of genome editing. Assumed in these publications, however, is a common *framework* for thinking about the moral permissibility of human genome editing. It consists (though not always) of distinguishing between somatic and germline changes, as well as between treatments and enhancements.

While this framework is useful and widespread, it has recently come under attack. Some scholars suggest that framing the moral debate with these two distinctions is unsound, particularly because the distinctions are ambiguous, and they ignore other relevant considerations. If these critiques against the framework are true, it would be difficult to accurately deliberate on human genome editing. This chapter considers these critiques and assesses their legitimacy. I argue that although these critiques are, in part, successful in exposing some difficulties of the framework, the framework is nonetheless feasible with a few revisions. Given the recommended revisions, I conclude with a revised framework that will provide a foundation for accurately conceptualizing

and deliberating on whether we should edit the human genome throughout the thesis. The goal here is not to discard the current framework or distinctions, but merely to improve them.

2. The Distinctions

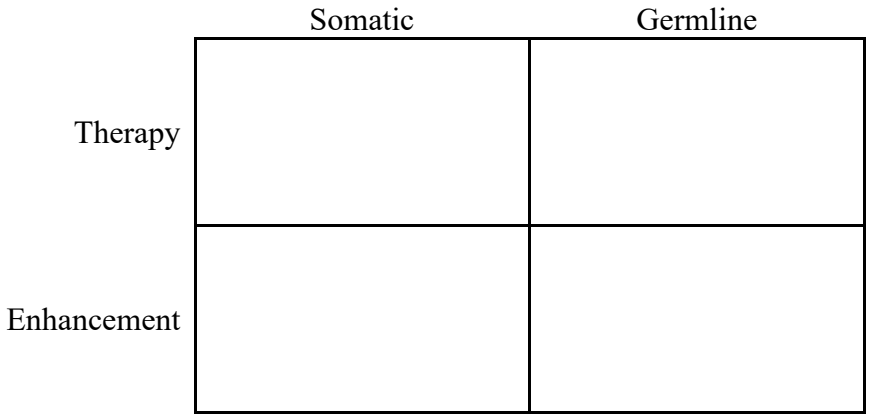
Moral deliberation, on any matter, should proceed after the relevant facts are considered. It would be a grave mistake to attempt to consider the *rightness* or *wrongness* of a particular topic when it is only partially grasped. For instance, determining whether medical assistance in dying is morally permissible depends on many factors, including whether the process involves killing or letting die, whether the patient has an irremediable condition, whether the patient is fully informed, whether the patient's pain is physical or mental, and so on. If some relevant considerations are missed, there is a possibility that our moral deliberation can be untenable. The same is true for human genome editing. Our framework should accurately represent the matter in question.

The common way of thinking about human gene editing includes distinguishing between somatic and germline genetic changes, and between treatments and enhancements. The somatic-germline distinction aims to differentiate the heritability of the genetic change. Genetic changes made to somatic cells which may include skin, heart, or brain cells, *will not* get passed on to future offspring.[2] Changes to the germline, however, including changes to reproductive cells or early embryos, *will* get passed on to future offspring.[3] Hence, germline changes allow us to alter the gene pool by changing the genes of future generations, whereas somatic changes stop at the individual.

Furthermore, the treatment-enhancement distinction aims to identify another aspect of human genome editing. Treatments generally aim to cure genetic diseases, such as Huntington's disease, sickle cell anemia, cystic fibrosis, muscular dystrophy and so on.[4] Conversely, enhancements usually improve the individual more than they otherwise would have been without

the genetic change. Some examples of enhancements include an increase in muscle growth, cognitive abilities, and perhaps even being more optimistic. These distinctions collectively inform the human genome editing debate. This framework can be conceptualized as follows:

Figure 1



2.1 Ethics Statements, International Policy Documents, and Surveys

Numerous ethics statements, international policy documents, and surveys use the above distinctions as a deliberative framework to identify a position on the permissibility of human genome editing.[5] Treatments have traditionally received more support, perhaps due to their resemblance to medicine, while enhancements have not been well received. Somatic changes have generally been accepted, while germline changes are typically deemed contentious and controversial.

Between 2015-2018, there have been 61 ethics statements released by the international community.[6] Of the 61 reported ethics statements, 54% explicitly claim that all forms of germline editing are impermissible,[7] while 11% remain open to reconsidering germline changes for treatment purposes in later years.[8] 5% of the statements suggest that germline gene editing should not be ruled out as impermissible, while the remaining 30% remain ambiguous on the matter, suggesting that more investigation is needed to draw a conclusion.[9]

Multilateral bodies including United Nations along with its affiliate bodies, The United Nations Educational, Scientific and Cultural Organization (UNESCO), The World Health Organization (WHO), and The Organization for Economic Co-operation and Development (OECD) have also established a position on human genome editing.[10] UNESCO's International Bioethics Committee (IBC) released a document suggesting that somatic treatments should be permissible, while there should be a ban on all germline modification.[11] This position is premised on both moral and safety concerns.[12]

In addition, surveys have been made available to citizens in several countries. A survey published by the journal *Science* indicated that various respondents in the U.S. were in favour of treatments (somatic and germline), while largely opposing all forms of enhancements.[13] In the UK, one study found that "76% of people…are in favour of therapeutic germline genomic editing to correct genetic diseases in human embryos, but…there was little appetite for germline genomic editing for non-therapeutic purposes."[14] Others surveys have reported similar sentiments and all use the somatic-germline and treatment-enhancement distinctions in the deliberative process.[15]

3. Critiques

This framework is useful for a few reasons. It is easily accessible to the scientific and non-scientific communities alike. That is, it can be understood and used to reach a wide audience. Furthermore, it has been used to make progress in considering the permissibility of human genome editing. The various documents that have used this framework have taken a position on the matter and derived basic guidelines around its use. Some scholars, however, have suggested that the framework is nonetheless untenable. I have summarized the most relevant critiques as follows:

(1) The distinctions are ambiguous: the somatic-germline and treatments-enhancements distinctions are not clear nor discernable distinctions.

(2) The current framework ignores relevant considerations: there are features of the human genome debate that are missed with this framework but should nonetheless inform our moral deliberation.

Considering these critiques is important to ensure accurate and robust deliberation on the ethics of human genome editing. I consider and assess their legitimacy in turn.

3.1 The distinctions are ambiguous

The first and perhaps biggest concern about the somatic-germline and treatment-enhancement distinctions is that although they may seem reasonable *prima facie*, they become unclear when we attempt to differentiate between them. In other words, they become blurrier the more we analyze them. Regarding the distinction between treatments and enhancements, Francoise Baylis considers it unhelpful. She says,

> "Descriptively all treatments are enhancements in the sense that all treatments aim to improve an individual by correcting an actual or perceived deficiency in relation to 'normal' abilities…As such, all human genome editing is a form of enhancement; it is just that some of the enhancements will be health-related and others not. And among those enhancements that are health-related, some will aim to 'treat,' while others will aim to 'prevent.'"[16]

Both "enhancements" and "treatments" improve individuals because they leave them better off than they were previously. Treatments are, at least on a basic understanding, a kind of enhancement even if it is primarily a health related one. If we conceptualize treatments and enhancements in this way, conflation seems inevitable.

Josephine Johnston, agreeing with Baylis that the treatment-enhancement distinction is blurry, identifies vaccination and birth control as examples that illustrate the difficulty of clearly separating treatments from enhancements.[17] Vaccination and birth control can be understood, on some definitions, as treatments, while at the same time, as enhancements on others. She says,

> "Depending on which version of the treatment-enhancement distinction is used, a vaccination is an enhancement because it confers a benefit not generally found in humans, or it is a treatment because it prevents disease. As another example, birth control does not generally aim to treat or prevent disease, but to enable the user to prevent pregnancy. This goal has medical benefit to the user, since being pregnant poses more medical risks than not being pregnant, and birth control is widely understood to be a standard medical technology and an appropriate part of medical care. Yet preventing pregnancy is also arguably a kind of enhancement since it creates a new ability—to have heterosexual intercourse without getting pregnant—that surpasses the preexisting limitations of the human body."[18]

While the examples of vaccination and birth control are seemingly unrelated to human gene editing, other examples illustrate the same problem and relate to our topic.

One example, in particular, is editing the *KL* gene to increase the production of the protein Klotho. Not only may this prevent neurodegenerative diseases like Alzheimer's but may also enhance cognition at the same time.[19] This would constitute a treatment because it prevents Alzheimer's, yet also an enhancement because it increases cognitive abilities beyond what the individual would have had without Klotho production.[20] The difficulty of categorizing these cases show that our distinctions are, at least to some extent, ambiguous.

Not only do some scholars argue that the treatment-enhancement distinction is ambiguous, but the same is true, although perhaps to a lesser degree because of its biological grounding, for the somatic-germline distinction. Johnston notes,

> Alterations in germ cells or embryos might not appear in all of the resultant person's cells and therefore might not be passed onto future generations…one of the babies whose genes had been editing by He Jiankui was reported to be mosaic for the introduced gene variant, which suggests that some of the child's germ cells will contain the change and some will not.[21]

The Jiankui case clearly identifies a further difficulty in attempting to distinguish between somatic and germline changes, because mosaic gene variants fall somewhere in the middle; they are in some sense, both. Hence, where should mosaic variants be placed in our categorical distinctions?

This difficulty, at least for Johnston, suggests that the somatic-germline distinction too is also ambiguous.

3.2 Are the distinctions ambiguous?

It is a difficult, and seemingly impossible task to capture all the necessary and sufficient conditions of our ideas or concepts. Many bioethical concepts, including justice, autonomy, beneficence, and non-maleficence are still used in moral deliberation, despite opposing and conflicting accounts about what they mean. Disagreement seems inevitable whenever a concept is conceptually considered. This same is true in differentiating between treatments and enhancements. While some scholars, like Eric Juengst, think it is possible to differentiate between therapeutic and enhancement forms of genetic intervention,[22] others remain unconvinced.

While Johnston reveals the difficult task of distinguishing between therapy and enhancements, these conclusions are often exaggerated. They usually generalize, from a small sample of cases, that all the other cases must be similarly ambiguous. Although some genetic changes indeed possess both a therapeutic and enhancing component, this does not show that every other change is indeed similar. This critique does not rule out the *clear* cases of treatments and enhancements.

One problem that leads to conflation is the lack of clear criteria that distinguish between treatment and enhancement. Without any criteria, ambiguity seems to be inevitable. While providing criteria is not the goal of this chapter, a few helpful ways to distinguish between treatments and enhancements are to:

1. Consider its *role* in alleviating and preventing suffering or physical pain.
2. Consider the primary *motive* behind the change.

Treatments generally serve a role in alleviating physical pain, often by eliminating debilitating diseases. The role of enhancements usually is not to prevent physical pain, but to improve human capacities. This, along with considering the motive or intention behind the genetic change, is helpful for our framework. Is the genetic change primarily being made to cure a disease or to create better athletes or something else? For instance, if prospective parents decided to change their children's hair colour because they believed "it just looks better," this can help determine that the kind of change we are dealing with.

Let us consider an example. Suppose two prospective parents possess the genes that cause muscular dystrophy, a rare muscle disorder that often leads to debilitating forms of muscle weakness.[23] There is a good chance that their children will inherit muscular dystrophy and experience mild to severe muscle weakness throughout their lives. Assuming it was safe and legal, suppose the prospective parents decided to remove the genes that cause muscular dystrophy using CRISPR-Cas9 so that their children did not inherit muscular dystrophy. The role of this change seems to be preventing muscular dystrophy, while the motive, though harder to identify, is most likely to prevent their children from living with pain caused by the disease.

Alternatively, suppose two prospective parents who did not have any disease-causing genes, sought to make their children physically stronger. Perhaps they attempted this by editing the *MSTN* gene and reducing muscle inhibitor proteins that result in increased muscle growth.[24] If this genetic change were successful, the role here would be giving their children a genetic predisposition to increased physical strength. While the motive, though harder to identify, is probably something other than preventing any foreseeable physical pain, perhaps to make them more athletic, less prone to injury, more attractive, or something else entirely. This significantly differs from the prospective parents wanting to prevent muscular dystrophy.

Returning to Johnston's example of vaccination, while it can be "an enhancement because it confers a benefit not generally found in humans, or…a treatment because it prevents disease,"[25] it seems clear that vaccination is primarily intended to prevent disease, rather than to enhance. Only as a collateral consequence, there is an attained benefit. The *motive* behind vaccination is usually to seek immunity from an illness, rather than gaining an edge over our peers. The *role* is the provision of antibodies to fight an anticipated virus (i.e., that causes pain).

While there are important genetic modifications that are difficult to categorize, the distinction between therapy and enhancement is not as unfeasible as Johnston and Baylis suggest. They should still inform our deliberation. The heritable genetic enhancements I will consider in the subsequent chapter are those that seek to augment the physical, intellectual, and sometimes behavioral capacities of contemporary and subsequent generations, for instance by making human beings stronger, more intelligent, possibly even more optimistic, and so on.

Comparatively, there seems to be an obvious and clear difference between genetic changes that seek to eliminate Huntington's Disease, cystic fibrosis, sickle cell disease, and those that seek to make human beings stronger or improve their cognitive abilities. While there may be cases that fall in between or are unclear, perhaps it is not suggestive that the distinctions are ambiguous, but that we need to acknowledge some outlier or in-between cases.

The same is true of the somatic-germline distinction. There is the possibility of mosaic variants that are in a category in-between somatic and germline genetic changes. This seemed to have happened with Jiankui's (highly unethical) experiment in 2018. The result of mosaicism, however, seemed to have been more a result of an error, rather than the intended goal. Jiankui sought to make edit the germline but failed to do so and it resulted in a mosaic variant.[26] It would be strange to assume that someone would want to intend a mosaic change, but its possibility

remains and should be acknowledged. Hence, the first recommended revision to our deliberative framework is that *we should recognize a relevant grey area between our distinctions*. This allows for a more comprehensive and accurate framework that acknowledges that some cases are ambiguous and require further deliberation.

3.3 The current framework ignores relevant considerations

Not only do some critics claim that the lines are ambiguous, but they also miss relevant considerations that should form part of our deliberation. Regarding the somatic-germline distinction, Tim Lewens claims that the bioethical literature has largely focused on "genetic" forms of germline inheritance, whereas "non-genetic" germline inheritance, or epigenomic inheritance, has been largely ignored.[27] He says, "there is a growing body of work indicating that inheritance can be achieved through a variety of non-genetic mechanisms. Some of these mechanisms involve the inheritance of difference mediated via differences in non-genetic germline structures."[28] In this case, we have ethically noteworthy cases of epigenome editing that are largely missed in our discussion.

Whereas genome editing can use CRISPR-Cas9 to edit the DNA sequence itself, epigenome editing can use CRISPR-Cas9 to edit DNA methylation patterns, which can determine gene expression without changing the genome sequence.[29] Lewens suggests that both genomic and epigenomic editing are both morally relevant because they can achieve similar outcomes. The possibility of heritable changes that affect future offspring is not only reserved for genomic editing, as epigenome editing can determine which and how genes are expressed.[30]

Regarding the treatment-enhancement distinction, some relevant considerations, I think, are missed. It seems that some changes fall under an "aesthetic" category that are unaccounted for in our deliberative framework. Suppose someone might want to make a change to their offspring

that is based primarily on preferences, such as hair colour, eye colour, or whether one's earlobes are attached to one's head. Changing these genes associated with hair colour, eye colour, or earlobe attachment do not seem to be treatments, because no 'disease' is being cured or prevented, nor do they seem to be enhancements because there would not be any notable improvement to the individual. This genetic change, then, would seem to be in a unique category of its own.

Unless someone possessed a mental hierarchy of desirable traits that considered attached earlobes as praiseworthy, or reprehensible, then on their view they might believe editing this trait might be a treatment or an enhancement, depending on where the trait ranked in their hierarchy. But even on this curiously absurd view, the changes would seem to be subjective preferences. Having attached earlobes does not seem to be inherently better than having detached earlobes. One is not left any better or worse. It seems to be more a matter of preference. Whether parents should be given a choice to change aesthetic traits in their offspring is an important question to consider and will be considered in chapter 4. It seems, however, that our distinctions miss this relevant third category that falls outside "treatments" and "enhancements."

3.4 Does the current framework ignore relevant considerations?

Lewens brings up a good consideration about the possibility of epigenomic editing being morally comparable for us to broaden our deliberation. But although there may be good reasons to deliberate on this matter, it is right to suggest that it should be included in the same discussion as genomic editing? Lewens rightly notes that the bioethical literature has largely ignored this topic, but perhaps this is suggestive, contrary to what he might think, that there is good reason why it is not discussed. Perhaps epigenomic editing should be treated as a problem of its own or is not as relevant as genomic editing.

My main concern with epigenomic editing is that the science is not entirely clear regarding its heritable effects in humans. Lewens himself notes that the scientific consensus about epigenomic editing has historically been received with skepticism by the scientific community and that only recently that there has begun active research on the topic.[31] Eric Miska and Anne Ferguson-Smith describe epigenomic inheritance as being an important factor in some plants, but although it has implications for humans, it remains unclear to what extent it has a significant effect in mammalian species.[32] To include epigenomic editing as part of our deliberation would seem too soon unless it is shown to possess a significant contribution to heritability.

While there still needs to be more research on the effects of epigenomic editing in humans, perhaps we can at least remain open to its possibility. It seems right, as Lewens suggests, that our ethical concern with genomic inherited changes has to do with its ability to be "passed on to the next generation."[33] If it becomes evident that epigenomic editing can cause inherited changes to future offspring, at least to a significant extent in humans, then it would be reasonable to broaden the approach to include epigenomic alterations as well.

Tentatively remaining open to the possibility of including epigenomic germline alterations seems like a viable path forward. It should, as Lewens argues, remain relevant to the discussion of human gene editing, unless, of course, the scientific data suggests otherwise. Therefore, including this consideration into our deliberative framework seems possible without affirming it entirely: *we should tentatively widen the germline category to not only include genomic changes, but potentially epigenomic changes as well by distinguishing between heritable and non-heritable changes.* Non-heritable changes would include somatic changes, whereas heritable changes include genomic changes as well as (tentatively) remaining open to the possibility of epigenomic alterations.

Furthermore, in section 3.3, we saw that there is an alternative third category that is being missed between the treatment-enhancement distinction, namely, that of aesthetic modifications. My suggestion, then, is that *we should move away from distinguishing between treatments and enhancements and towards more comprehensive categories, such as therapeutic and non-therapeutic genetic changes.* Distinguishing between therapeutic and non-therapeutic genetic changes is beneficial because it captures enhancements and aesthetic modifications within the *non-therapeutic* category. It also allows for the deliberation of aesthetic genetic changes as its own moral issue; the literature has generally avoided deliberating solely on aesthetic changes or has mistakenly considered them as kinds of enhancements.

As for the *therapeutic* category, it has been revised from treatments to therapeutic (genetic changes). This has been largely in part to facilitate the contrast with *non-therapeutic* genetic changes. Conceptually this distinction has essentially remained largely unchanged as treatments and therapy tend to be considered synonymous. One added practical benefit, however, could be that "therapeutic" genetic changes can neatly fit alongside the already existing field of gene therapy.[34] Using CRISPR-Cas9 to correct defective genes is a form of gene therapy and therefore "therapeutic" seems more fitting compared to "treatments." While there are of course grey cases that fall in-between therapeutic and non-therapeutic conditions, distinguishing between therapeutic and non-therapeutic appeals to the unambiguous cases discussed at length in section 3.2.[35]

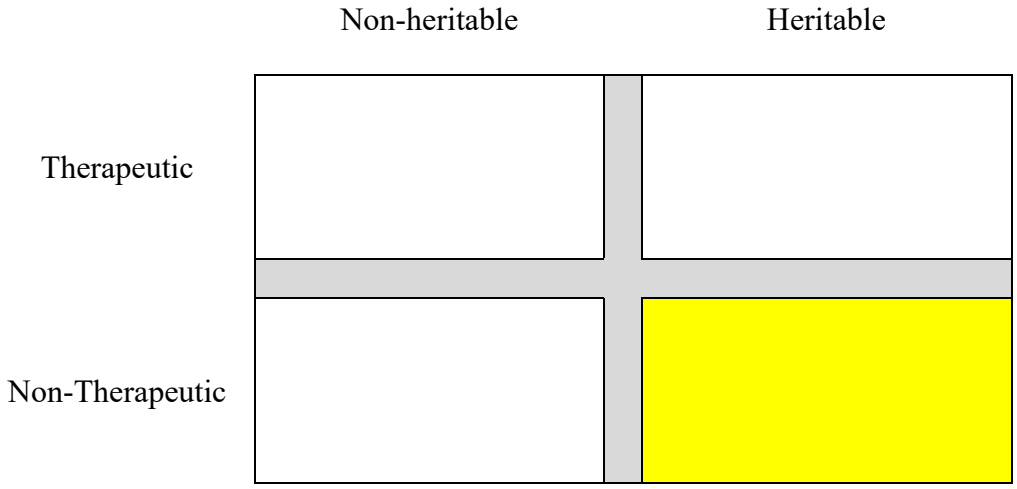
4. A Revised Framework

Many of the scholars who propose the above critiques do not provide any substantial alternative ways of conceptualizing the current framework. This paper has proposed some recommended revisions to our current framework that allows us to deliberate more accurately on human germline editing. The following three considerations recommendations were considered:

1. *We should recognize a relevant grey area between our distinctions.*
2. *We should tentatively widen the germline category to not only include genomic changes, but potentially epigenomic changes as well by distinguishing between heritable and non-heritable changes.*
3. *We should move away from distinguishing between treatments and enhancements and towards more comprehensive categories, such as therapeutic and non-therapeutic genetic changes*.

While there have been strong criticisms against the previous framework, it still seems feasible with some added revisions. It is important to note that the intention here was not to discard the use of the treatment-enhancement or somatic-germline distinctions but to revise them to deliberate more accurately on the debate around human genome editing. Our revised framework (i.e., Figure 2) represents a better, revised, framework for deliberating on the moral permissibility of human genome editing. Having a better understanding of these distinctions, we can now turn our attention to examining which heritable non-therapeutic genetic changes, if any, are morally permissible.

Figure 2



This chapter considered two common critiques that are presented against the framework. With a clearer understanding of how we might conceptualize the human gene editing debate, we can now turn to consider the ethical and moral parameters of a specific kind of human genome editing. While each of the areas within the framework are noteworthy, the rest of the thesis will be dedicated to deliberating on the moral permissibility of *heritable non-therapeutic genetic changes* (as highlighted in yellow above). These include heritable genetic enhancements and aesthetic changes.

Notes

[1] Eric S. Lander, et al., "Adopt a Moratorium on Heritable Genome Editing," *Nature* 567, no. 7747 (2019): pp. 165-168, https://doi.org/10.1038/d41586-019-00726-5.

[2] Jennifer A. Doudna and Samuel H. Sternberg, *A Crack in Creation: Gene Editing and the Unthinkable Power to Control Evolution* (Boston: Mariner, 2018), 158.

[3] Ibid.

[4] Ibid., 13.

[5] For this framework being used in other policy documents, see Johnston, 2020.

[6] Carolyn Brokowski, "Do CRISPR Germline Ethics Statements Cut It?," *The CRISPR Journal* 1, no. 2 (2018): 115.

[7] Ibid., 122.

[8] Both the Bioethics and Law Observatory of the University of Barcelona's *Document on Bioethics and Gene Editing in Humans* and The Academy of Medical Sciences' *The Academy of Medical Sciences' Response to the Nuffield Council on Bioethics 'Genome Editing and Human Reproduction' Call for Evidence* agree that therapeutic and not enhancement germline changes should be sought. The Commission on Genetic Modification and Health Council of the Netherland's *Editing Human DNA: Moral and Social Implications of Germline Genetic Modification* remains ambiguous on this issue.

[9] Carolyn Brokowski, "Do CRISPR Germline Ethics Statements Cut It?," 122.

[10] See "The Governance of Human (Germline) Genome Modification at the International and Transnational Levels" in Boggio, et al., 2020.

[11] UNESCO. "International Bioethics Committee: Updating Its Reflection on the Human Genome and Human Rights." SHS/YES/IBC, 2015: 7.

[12] The first and second Advisory Committee statements by the WHO in 2019, along with *Gene Editing for Advanced Therapies: Governance, Policy and Society* by the OECD in 2018 hold the same view.

[13] Ditram A. Scheufele, et al, "U.S. Attitudes on Human Genome Editing," *Science* 357, no. 6351 (2017): 553.

[14] Andrew McGee, "Using the Therapy and Enhancement Distinction in Law and Policy," *Bioethics* 34, no. 1 (2020): 70.

[15] Tristan McCaughey, et al, "A Global Social Media Survey of Attitudes to Human Genome Editing," *Cell Stem Cell* 18, no. 5 (2016): 569-570.

[16] Françoise Baylis, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing* (Cambridge: Harvard University Press, 2019), 62.

[17] Josephine Johnston, "Shaping the CRISPR Gene-Editing Debate: Questions About Enhancement and Germline Modification," *Perspectives in Biology and Medicine* 63, no. 1 (2020): 144.

[18] Ibid.

[19] Eric T. Juengst, et al, "Is Enhancement the Price of Prevention in Human Gene Editing?," *The CRISPR Journal* 1, no. 6 (2018): 353.

[20] See also The Commission on Genetic Modification and Health Council of the Netherland's *Editing Human DNA: Moral and Social Implications of Germline Genetic Modification*'s discussion on the difficulty of defining treatments and enhancements.

[21] Josephine Johnston, "Shaping the CRISPR Gene-Editing Debate: Questions About Enhancement and Germline Modification," 144.

[22] Juengst, Eric T. "Can Enhancement be Distinguished from Prevention in Genetic Medicine?." *The Journal of Medicine and Philosophy* 22, no. 2 (1997): 125-142.

[23] "What Is Muscular Dystrophy?," Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, October 27, 2020), https://www.cdc.gov/ncbddd/musculardystrophy/facts.html.

[24] Helge Amthor et al., "Lack of Myostatin Results in Excessive Muscle Growth but Impaired Force Generation," *Proceedings of the National Academy of Sciences* 104, no. 6 (2007): 1835-1840, https://doi.org/10.1073/pnas.0604893104.

[25] Josephine Johnston, "Shaping the CRISPR Gene-Editing Debate: Questions About Enhancement and Germline Modification," 144.

[26] "China Jails 'Gene-Edited Babies' Scientist for Three Years," BBC News (BBC, December 30, 2019), https://www.bbc.com/news/world-asia-china-50944461.

[27] Tim Lewens, "Blurring the Germline: Genome Editing and Transgenerational Epigenetic Inheritance," *Bioethics* 34, no. 1 (2020): 11.

[28] Ibid.

[29] Ibid., 10.

[30] Ibid., 11.

[31] Ibid., 9.

[32] Eric A Miska, and Anne C. Ferguson-Smith, "Transgenerational Inheritance: Models and Mechanisms of non-DNA-Sequence-Based Inheritance," *Science* 354, no. 6308 (2016): 63.

[33] Tim Lewens, "Blurring the Germline: Genome Editing and Transgenerational Epigenetic Inheritance," 11.

[34] See the glossary for a definition of gene therapy.

[35] While some authors have used terms such as "heritable" and "non-therapeutic" (along with their counterparts), they are often used as synonyms with "germline changes" and "enhancements." Hence, although these are not novel distinctions as such, I suggest that we should utilize them precisely for the distinctive reasons provided previously.

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2

HERITABLE ENHANCMENTS: PART I

1. Introduction

When examining the ethics of human genome editing, there are relevant distinctions to consider, for instance, whether or not the changes are heritable, and whether the changes are for therapeutic or non-therapeutic purposes. This chapter analyzes a specific type of heritable non-therapeutic genetic change: *heritable genetic enhancements*. At its most basic level, these changes seek to enhance the genes of contemporary and subsequent generations by augmenting their physical and intellectual capacities.[1] In this chapter, I will consider and assess some arguments that suggest a positive case in favour of heritable genetic enhancements.

To grasp these changes more accurately, it is helpful to juxtapose them with other kinds of genetic changes. Enhancements, as will be used in this paper, stand apart from therapeutic changes that seek to prevent or cure genetic diseases, such as sickle cell anemia, cystic fibrosis, or Huntington's. While these genetic changes may also "augment" physical capacity in some broad sense, they ultimately serve a pain-relieving function, as opposed to an enhancing one.

Enhancements also stand in isolation from an alternative kind of non-therapeutic genetic change, namely aesthetic modifications.[2] These changes typically seek to alter physical appearance without the intent to enhance or prevent disease. Rather, they make (seemingly neutral) changes to one's eye colour, hair texture, or whether one's earlobes are attached.[3] Unlike aesthetic changes, enhancements seek to deliberately improve human beings beyond what they otherwise would have been without the genetic change, for instance by increasing muscle mass or cognition.

It is important to note that there may be some genetic enhancements that conceivably overlap with other kinds of genetic changes, for instance, a genetic change that possesses a therapeutic and enhancing component. I have previously used editing the Klotho gene as a working example of this. Not only can upregulating the Klotho protein serve a therapeutic purpose by preventing neurodegenerative diseases but can also enhance cognition.[4] While these grey examples are relevant and deserving of moral deliberation, this chapter focuses on enhancements for which the augmentation of physical and cognitive capacities is the primary and sole objective.

Furthermore, heritable genetic enhancements have a lasting multigenerational impact as the changes are passed onto future generations. Genetic changes become transmissible from parent to offspring when they are made to reproductive cells,[5] or in early embryos. It is precisely this ability to manipulate the genes of future humans where a lot of the moral contention exists. It yields an unprecedented capacity to significantly change the gene pool.[6] This creates a moral responsibility towards subsequent generations, as these genetic changes will inevitably shape them, whether for good or ill.

It comes as no surprise that heritable genetic enhancements constitute a great portion of the controversy within the human genome editing debate. While several countries currently have restrictions on heritable (or germline) genetic changes,[7] especially for enhancement purposes, several ethicists support heritable genetic enhancements.[8] Among these ethicists is John Harris, who argues in favour of enhancements in general, but also for heritable genetic enhancements. Drawn largely from his book, *Enhancing Evolution*, I consider and evaluate two of his arguments, one primary and one supplemental, that support heritable genetic enhancements.

The primary argument considers some enhancements as moral duties, while the second argument suggests that our reproductive freedoms should permit our engagement with heritable

genetic enhancements. Although these arguments are forceful, I will argue that they do not establish a moral obligation to pursue heritable genetic enhancements. That is, they do not provide a strong *positive* case in their favour. I support this conclusion by considering a few objections offered in response to each of Harris' arguments.

2. Genetic enhancements as moral duties

Although *Enhancing Evolution* was written slightly before the advent of CRISPR-Cas9, Harris' arguments are nonetheless supportive of and applicable to novel forms of genome editing. In fact, he has recently endorsed the genetic modification of human embryos for enhancement purposes.[9] His arguments, then, are relevant to our purposes here. For Harris, not only are enhancements morally permissible but "in some cases there is a positive moral duty to enhance."[10]

Harris suggests that we (as humans) already deem enhancements as permissible. He says no one "actually thinks that there is anything in principle wrong with the enhancement of human beings."[11] He provides a few examples to support this claim, citing our acceptance of eyeglasses and vaccination, which he takes to be clear and obvious examples of enhancements. If we assume eyeglasses and vaccination are permissible, then Harris thinks we should also consider other enhancements as permissible—genetic or otherwise. Hence, there is nothing morally wrong with enhancements as such.

Furthermore, he has suggested that there are some circumstances when we possess a moral duty to pursue and implement enhancements. This duty largely stems from the obligation to "create the best possible child, a child who will be the healthiest, most intelligent and most resilient to disease reasonably possible given the parents' other priorities."[12] If we can enhance our children and give them a better life, we should. It would be wrong if we fail to give our children the best possible life.

I venture to suggest that this central idea is maintained by a variety of philosophers and ethicists, although construed in different ways. Julian Savulescu, for instance, espouses the principle of Procreative Beneficence, suggesting that "couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information."[13] Similar to Harris, Savulescu derives a moral duty from the obligation to give our children the best possible life. Comparably, to act against the principle of Procreative Beneficence, at least without sufficient reason, would be wrong.

While Savulescu's principle was originally defended in the context of *in vitro* fertilization (IVF) and preimplantation genetic diagnosis (PGD), it has been recognized by some philosophers as compatible with contemporary gene-enhancing technology.[14] Walter Viet suggests the principle of Procreative Beneficence, "commits one to accepting the parental obligation to genetically enhance their prospective children, i.e. embryos, a position Savulescu doesn't explicitly endorse but I argue is committed too."[15] While there should be some hesitancy to ascribe conformity between Savulescu's commitments and the obligation to genetically enhance future children, the association seems tenable.[16]

In this chapter, I will focus on Harris' argument drawn from *Enhancing Evolution* that suggests we have a moral obligation to pursue enhancements in general, but particularly heritable genetic enhancements. While my analysis is narrowly aimed at Harris' argument, its implications broadly apply to similar arguments that conceptualize (genetic) enhancements as moral duties. While Harris does not formalize his argument, I summarize the main features as follows:

i. Enhancements are good for humans.[17]

ii. If we can implement enhancements safely, while avoiding harms, we should.[18]

iii. We can implement enhancements safely, while avoiding harms.

iv. Therefore, we should implement enhancements.

Despite widespread worry surrounding human enhancement, Harris conceptualizes them as incontrovertibly good things. He asks,

> Wouldn't it be wonderful if we humans could live longer healthier lives with immunity to many of the diseases like cancer and HIV/AIDS that currently beset us? Even more wonderful might be the possibility of increased mental powers, powers of memory, reasoning, and concentration, or the possibility of increased physical powers, strength, stamina, endurance, speed of reaction, and the like. Wouldn't it be wonderful?[19]

Harris rhetorically assumes the answer. Of course, it would be wonderful to enhance human capabilities, they are good things.

Yet understanding enhancements as good things for humans does not necessarily establish a moral obligation to pursue them. It could be that these enhancements may lead to severe social harm or pose an extraordinary amount of risk to the individual and their descendants. Additionally, pursuing genetic enhancements may even be an inappropriate use of time and resources, especially if other concerns should be given priority. The moral duty to enhance depends largely on the consequences and repercussions associated with the genetic changes.

For Harris, the concerns around enhancements, like the problems of accessibility, "playing God," associated health risks, safety, and so on, are not legitimate reasons to prevent our engagement with enhancements. Harris tackles some of these concerns in chapters 1-3 but more extensively in chapters 7-8 of *Enhancing Evolution*. Ultimately, he suggests that we can implement enhancements safely, while reasonably avoiding corresponding harms. While I am not convinced Harris successfully responds to all the above-mentioned concerns, I will nonetheless assume he does in this chapter.

Assuming enhancements are good things and can be implemented safely, the moral duty to enhance becomes evident. We should implement enhancements that will allow human beings to live better, healthier lives. To refuse would be to deny ourselves, and future generations, a better life. Harris says, "we must not fail to make changes that could be made which will avoid harm to future people or which would benefit them in ways that cannot be achieved unless these enhancements are put in place."[20] Hence, (at least) some heritable genetic enhancements should be pursued as moral duties.

2.1 Analysis

For this central argument, I will consider two objections to Harris' suggestions that genetic enhancements should be understood as moral duties. Firstly, Harris' usage of "enhancements" tends to be overly broad and untenable as he conflates therapy and enhancements as the same with no distinction. On this loose understanding of "enhancements," the treatment of genetic disease and the improvement of physical or intellectual capabilities are both collectively taken to be "enhancements." His position resembles some views presented in chapter 1.

There is some reason to think this conflation is indeed purposeful. Harris suggests, "The boundaries between treatment and enhancement, between therapy and enhancement, are not precise and often nonexistent, nor are these categories mutually exclusive."[21] Hence, it is precisely because Harris views the distinction between "therapy" and "enhancement" as unclear, that he resorts to categorizing both as "enhancements." As a consequence, Harris conceptualizes therapy and enhancements as homogenously good. It is *good* to treat genetic diseases, and it is also *good* to make humans physically stronger.

While I think the line between therapy and enhancement is clearer than is often supposed,[22] Harris' handling of therapy and enhancements as "good," in the same way is unsound. While I

would not deny that it would be good to treat genetic disease and good to be physically stronger, there does seem to be a relevant difference between the two. A difference, I think, that has a bearing on whether we have a moral duty to pursue these genetic changes.

Let us compare a heritable genetic change that seeks to eliminate sickle cell anemia and one that seeks to enhance physical strength. Sickle cell anemia affects hemoglobin production and usually restricts the amount of oxygen that is circulated in the body.[23] This often leads to severe problems, including stroke, frequent infections, episodes of pain, vision obstruction, and a reduced life span.[24] Those with sickle cell anemia can and certainly do live fulfilling lives, but they sometimes face obstacles of physical pain. As a result, we might suggest that it would be *good* to provide genetic therapy for sickle cell anemia so that the next generation can live a life without the disease.

Conversely, genetically enhancing physical strength would not relieve future generations from physical suffering, it would instead make them genetically predisposed to more muscle mass. Perhaps they would be able to easily perform physically demanding tasks, make them less prone to injury, and lead to a better quality of life, although these outcomes would largely depend on environmental factors. Overall, however, assuming that there are no adverse social and individual harms from making people genetically stronger, it may be reasonable to suggest that being stronger is also a *good* thing.

Yet when we compare curing sickle cell anemia and enhancing physical strength, it becomes clear that these genetic changes are *good* in very different ways, and for very different reasons. Curing sickle cell anemia is good because it prevents a significant amount of physical pain for future generations while enhancing physical strength is good because it can lead to better human capabilities. I venture to suggest that only in the former set of circumstances do we have a

pressing moral duty to pursue the genetic change. For if we abstain from providing genetic therapy for sickle cell anemia, or any other genetic disorder when it is in our power to do so, we deliberately allow physical pain.

On the contrary, if we refrain from providing a genetic change that enhances physical strength when it is in our power to do so, we prevent future generations from possessing a genetic predisposition to physical strength. Although it seems clear that we should try to prevent undue physical pain and therefore prevent sickle cell anemia, it is not clear that we have a moral duty to make people as strong as possible. While future generations may possess an added benefit if they were genetically enhanced with more strength, prospective parents are not immoral if they choose to focus on other ways to benefit them.

Other ways prospective parents can help will be by enrolling them into sports programs, getting them a gym membership, or helping them maintain a balanced and nutrient-rich diet. There does, however, seem to be a moral duty to pursue therapeutic genetic changes as it would harm future generations with physical pain. This is especially the case as there is no other way around removing sickle cell given its genetic cause.

Secondly, even if we assume that heritable genetic enhancements are good, in the morally obligatory sense, and can be implemented safely while avoiding harms, pursuing them is problematized when we are faced with the countless other goods we can provide for future generations. For instance, making sure we do not irredeemably pollute the Earth, making sure the society they are raised in provides equal and free opportunities, eliminating racism and sexism, making sure future generations can exercise their human rights, and so on.

While it would be ideal to implement all of these good things for future generations, it becomes too demanding if our standard is to unfeasibly provide future generations with *all* good

things. It is simply not possible. On the contrary, it is feasible to attempt to provide the most we reasonably can for future generations. An essential component of this would be to prioritize our resources, capital, and efforts towards the goods that will provide the most benefit and avoid the most harm.

Hence, even if heritable genetic enhancements are good and helpful things, the moral duty to pursue them diminishes when we are confronted with the innumerable other things that are better. Again, problems associated with food security, water scarcity, poverty, access to education, gender equality, climate action, disease, and so on may be more obliging than heritable genetic enhancements. Additionally, as will be considered in subsequent chapters, genes only contribute partly to physical strength and intelligence. That is, in the wrong environment, humans can even be less strong or intelligent compared to those non-genetically altered yet who maintained a healthy environment. My two objections assumed that enhancements are good and that they can be implemented safely while avoiding harms. Even if these are taken to be true, it is not clear that we possess a moral duty to pursue heritable genetic enhancements.

3. Genetic changes and reproductive liberties

Harris' second, albeit supplemental, argument that supports heritable genetic enhancements relies on our autonomy and reproductive liberties. It is generally accepted that good democratic societies are those that respect personal freedom and autonomy. They should allow their citizens to make their own choices and live according to the values they choose. There are, of course, reasonable limits to our autonomy, for instance when our actions harm other members of society, or perhaps more controversially when our actions harm ourselves. Excluding the above-mentioned conditions, citizens should generally be allowed to engage in the pursuits they consider worthwhile without societal or governmental restrictions.

As Harris suggests, our personal autonomy also extends to our reproductive choices.[25] Individuals possess the right to make their own reproductive choices, without the interference of the state or other members of society. For Harris, "Only serious real and present danger either to other citizens or to society is sufficient to rebut this presumption."[26] Consequently, if prospective parents decide to alter their own reproductive cells, or the genomes of their children, whether for enhancements or otherwise, their actions should be tolerated.

The onus is on those who wish to restrict the reproductive liberties of prospective parents to show why genetic modifications are either harmful or dangerous.[27] Harris says,

> Thus, the freedom to access reproductive technologies and indeed enhancing technologies or procedures is at the very least protected by the democratic presumption. Where these procedures are part of reproductive decision making they may well be a dimension of a fundamental of basic human right already established and widely recognized.[28]

Hence, if prospective parents desire to have enhanced children, the suggestion here is that their reproductive rights make these changes permissible. This argument reinforces the former by corroborating the legitimacy of pursuing heritable genetic enhancements. So long as there is no serious threat identified, our default perspective should be to allow enhancements—genetic or otherwise.

3.1 Analysis

Arguments like this one, it seems, inadvertently predict the future of human genome editing within liberal democratic societies. As gene-editing technology becomes more accessible, as Jürgen Habermas predicted in *The Future of Human Nature*, it will probably be a reference to personal autonomy that will allow enhancing technology to become widespread. The fast-evolving biohacking movement, premised on personal autonomy, is evidence of this.[29] The exception, of course, is if there is a case strong enough to suggest that allowing these will lead to severe societal consequences.

Yet while I do think heritable genetic enhancements may pose enough of a threat to limit its usage, at least temporarily given its potential for eugenics and problems with inaccessibility, these concerns will be considered in the subsequent chapter. For the goal of this chapter, I am particularly concerned about the *positive* case for heritable genetic enhancements, rather than a *negative* case against them. It is helpful to identify what this argument from autonomy seeks to establish. It seems to be establishing the correct *political* stance that the state should have towards genetic enhancements, along with the correct *social* stance that citizens should have towards genetic enhancements. It suggests that a hands-off approach is best when it comes to dealing with enhancing technology, assuming it does not pose any immediate danger.

Yet although this seems like the best approach to handle citizen engagement with enhancing technology (assuming it does not pose a serious threat), this proposal does not give us any *moral* reason to pursue heritable genetic enhancements—even if we possess the political or human right to. There are various actions that, although remain legally, socially, or politically permissible within a liberal democracy, are nonetheless *morally* wrong or that do not compel us to pursue them.

For instance, lying to a friend is generally considered unethical, although lying to a friend is not a criminal offence. In addition, owning a gun may be considered a right in various democratic societies, though we would not suggest that this right establishes a moral duty to own a gun. In the same way, although engaging in genetic enhancements may be legal in the future, as granted by our personal liberties, there is no moral reason to suggest that we should pursue them nor that they are morally permissible. This does not add anything, morally speaking, in favour of enhancements—genetic or otherwise.

4. Conclusion

This paper considered whether there is a *positive* case in favour of heritable genetic enhancements. There is reason to suggest that while heritable *therapeutic* genetic changes that relieve physical pain create a moral duty to pursue them, heritable genetic enhancements do not. Harris' suggestion that enhancements are moral duties, along with the suggestion that our reproductive liberties should permit our engagement with them, do not give us any moral reason to pursue them. In the next chapter, I will consider some moral reasons *against* heritable genetic enhancements.

While my critique here has narrowly focused on Harris' arguments, his ideas largely represent many of the common suggestions used in favour of heritable genetic enhancements. While considering all the versions of these arguments remains difficult given the contraints of the thesis, Harris represents a forceful case in favour of heritable genetic enhancements.

Notes

[1] Nick Bostrom, "Human Genetic Enhancements: A Transhumanist Perspective," *The Journal of Value Inquiry* 37, (2003): 493.

[2] John Harris refers to these as "morally neutral" in chapter 9 of *Enhancing Evolution*.

[3] These will be considered more extensively in chapter 4.

[4] Ci-Di Chen, et al., "Activation of the Anti-Aging and Cognition-Enhancing Gene Klotho by CRISPR-dCas9 Transcriptional Effector Complex," *Journal of Molecular Neuroscience* 64, no. 2 (2018): 175-184.

[5] I.e., sperm and egg cells.

[6] While there have been (obviously wrong) ways to control the genes of a given population through mate selection or forced sterilization, gene editing makes it possible to cut, edit, and add new genes.

[7] Françoise Baylis, et al., "Human Germline and Heritable Genome Editing: The Global Policy Landscape," *The CRISPR Journal* 3, no. 5 (2020): 365-377.

[8] Particularly Nick Bostrom.

[9] John Harris, "Should we genetically modify humans? Interview with Professor John Harris." The Oxford Uehiro Centre for Practical Ethics. November 14, 2017. Video, 17:02. https://www.practicalethics.ox.ac.uk/article/latest-youtube-video-interview.

[10] John Harris, *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton: Princeton University Press, 2010), 3.

[11] Ibid., 8.

[12] John Harris, "Gene Editing of Embryos Is Both Ethical and Prudent," October 20, 2017, https://leaps.org/gene-editing-is-both-ethical-and-prudent/particle-1.

[13] Julian Savulescu, "Procreative Beneficence: Why We Should Select the Best Children," *Bioethics* 15, no. 5-6 (2001): 414.

[14] See Walter Veit, "Procreative Beneficence and Genetic Enhancement," *Kriterion-Journal of Philosophy* 32, no. 1 (2018): 75-92.

[15] Ibid., 76.

[16] See Christopher Gyngell, Thomas Douglas, and Julian Savulescu, "The Ethics of Germline Gene Editing," *Journal of Applied Philosophy* 34, no. 4 (2017): 498-513.

[17] John Harris, *Enhancing Evolution: The Ethical Case for Making Better People*, 29.

[18] Ibid., 35.

[19] Ibid., 8.

[20] Ibid., 80.

[21] Ibid., 57.

[22] See chapter 1.

[23] "Sickle Cell Disease," National Heart, Lung, and Blood Institute, Accessed March 26, 2021, https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease.

[24] Ibid.

[25] John Harris, *Enhancing Evolution: The Ethical Case for Making Better People*, 75.

[26] Ibid., 72.

[27] Ibid., 74.

[28] Ibid., 79.

[29] Sigal Samuel, "How biohackers are trying to upgrade their brains, their bodies—and human nature," Last modified November 15, 2019. https://www.vox.com/future-perfect/2019/6/25/18682583/biohacking-transhumanism-human-augmentation-genetic-engineering-crispr.

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3

HERITABLE ENHANCMENTS: PART II

1. Introduction

November 2021 will mark three years since He Jiankui announced that he had created the world's first genetically modified babies. In the relatively short amount of time since this milestone, many significant events have unfolded. Jiankui was fined a large sum and given a prison sentence for violating the Criminal Law in China.[1] Various scientists and ethicists have called for a global moratorium on heritable human genome editing.[2] Jennifer Doudna and Emmanuelle Charpentier won the 2020 Nobel Prize in Chemistry for CRISPR-Cas9,[3] the gene-editing technology that made Jiankui's experiment possible.[4] And the human gene editing debate has notably caught public attention.

Globally, there are only a few countries that permit germline research, including the United States (with private funding), the United Kingdom, India, and China.[5] While some countries allow germline research, no country allows its use for reproduction (i.e., implanting an edited embryo into a uterus to create genetically-modified children).[6] The world largely remains in an ongoing deliberative process regarding heritable genome editing,[7] considering the "the technical, scientific, medical, societal, ethical and moral issues that must be considered before germline editing is permitted," if at all.[8]

The literature suggests there are diverging perspectives regarding whether heritable genetic changes should be permitted. Some think we *should* proceed with germline editing, whether for enhancements, disease prevention, or aesthetic modifications.[9] Others propose we *should only* edit

the germline to eliminate debilitating diseases like cystic fibrosis, sickle cell disease, Huntington's, and muscular dystrophy. And some argue for a precautionary approach and contend we *should not* edit the germline at all, especially considering there are alternative medical interventions, particularly *in vitro* fertilization, and preimplantation genetic diagnosis, that can accomplish similar therapeutic results.

In the previous chapter, I considered some moral reasons proposed by John Harris that argued in favour of heritable genetic enhancements. This chapter proposes an argument that suggests because it is likely that heritable genetic enhancements will yield significant harms and produce minimal good, we have moral reason not to pursue heritable genetic enhancements. To support this argument, I consider the problem of inaccessibility related to heritable genetic enhancements. As previously defined, heritable genetic enhancements refer to those genetic changes that seek to augment the physical, intellectual, and sometimes behavioral capacities of contemporary and subsequent generations. For instance, increasing muscle mass and intelligence.

2. The Argument

As is the case with many powerful technologies, determining what will happen if it is implemented is a difficult task. To a large extent, we are forced to speculate about what the consequences *might* be if we introduced heritable genetic enhancements. Yet while this is the case, we can make a probable case for what the likeliest outcome will be based on how our world is currently governed. While many bioethicists consider heritable genome editing worrisome, given its potential to lead to designer babies and eugenics, others assert these concerns are merely exaggerations.

In "Who's Afraid Big Bad (Gene Editing) Wolf?" Alta Charo presents a historical argument that challenges many of the concerns around heritable genome editing.[10] Charo identifies previous technological breakthroughs, including *in vitro* fertilization (IVF), surrogate motherhood,

preimplantation genetic diagnosis (PGD), and argues that although each of them received dystopian narratives before their introduction, they did not lead to disastrous consequences.[11]

Yet while Charo's assessment of previous technologies is fair, we should not simply assume that heritable genome editing will be the same as previous technologies. There is reason to think that heritable genetic enhancements are different from anything we have seen before. For instance, they give us the unprecedented ability to significantly alter the gene pool and to genetically alter future generations. This is no small feat. To support my suggestion against heritable genetic enhancements, my argument can be formalized as follows:

i. Heritable genetic enhancements can be used in good and harmful ways.

ii. If it is likely that heritable genetic enhancements will yield significant harms and produce minimal good, we have moral reason not to pursue heritable genetic enhancements.

iii. It is likely that heritable genetic enhancements will yield significant harms and produce minimal good.

iv. Thus, we have moral reason not to pursue heritable genetic enhancements.

Regarding premise *i*, heritable genetic enhancements appear to be instrumental, possessing the capacity to be used in good ways and bad. We can imagine that heritable genetic enhancements, at least in an ideal world, can be used in good ways. Everyone would be able to have fair access to the technology and use it in beneficial ways. Perhaps everyone would be a little stronger, smarter, and maybe even more optimistic. Alternatively, we can also imagine heritable genetic enhancements being used in harmful ways, perhaps if only a few individuals had access to the technology while everyone else did not. This would widen the gap between those who can access it and those who cannot. Both scenarios are conceivable.

Regarding premise *ii*, given our forward-looking position, if it seems more likely than not that introducing heritable genetic enhancements will lead to significant harms and produce

minimal good, then it seems as though we would have moral reason to refrain from implementing them. All things being equal, to knowingly introduce a technology that is likely to cause harm is wrong. Of course, some might be inclined to give a utilitarian response and suggest that if there is enough good that outweighs the harms, then it is not morally wrong to implement heritable genetic enhancements. While this is debatable, the premise particularly suggests that if it yields significant harms *and produces minimal good*, then we have moral reason not to pursue heritable genetic enhancements. A comparative example here might be to introduce a government-led software that spies and analyzes every citizen's technological device to detect for illegal activity. While this may provide some good by detecting some crime, it comes at the expense of invading everyone's privacy.

Regarding premise *iii* and conclusion *iv*, it logically follows that if it is likely that heritable genetic enhancements will yield significant harms and produce minimal good, then the conclusion that we have moral reason not to pursue heritable genetic enhancements is true. The argument, as it currently stands, is logically valid. Some might be inclined to disagree or challenge premise *iii*. Perhaps heritable genetic enhancements will not lead to significant harms and might even lead to very good outcomes. In support of premise *iii*, and the conclusion that follows, I will consider a commonly cited argument against pursuing heritable genetic enhancements, namely, whether heritable genetic enhancements will be accessible to everyone and what the consequences will be if they are not.

It is important to note that there is currently an epistemic gap concerning the safety of heritable human genome editing. There is a possibility that editing the germline can lead to serious unintended and off-target activity. As was mentioned in the first International Summit on Human Gene Editing, and reinforced in the second, it would be irresponsible to proceed with heritable

genome editing "until safety issues were resolved."[12] This, then, creates a considerable barrier given the level of risk posed to future generations.

The assessment of weighing the risks and rewards remains a difficult task, especially if the consequences are unknown. Heritable genome editing may create more problems than it solves or may never be safe enough to implement. Yet while safety is a big concern, I prefer to leave this issue aside and grant this premise by operating on the assumption that science will one day be able to make heritable genetic changes in a minimally invasive and harmless way. Although this remains hypothetical, let us assume that it is only a matter of time before science makes this possible.

2.1 Inaccessibility and Inequality

It would be ideal if everyone, regardless of their socio-economic status and geographical location, would be able to access gene-editing technology for themselves and their descendants. Additionally, it would also be ideal if everyone used the technology in good ways that led to an increase in human flourishing. On a sobering assessment of our world, however, given our neoliberal economic structures and existing inequalities, it seems likely that heritable genetic enhancements will not be implemented in fair and accessible ways. This will likely result in increased inequalities. Furthermore, the good that might come will probably only be in the hands of a select few, those affluent enough to access it.

In her insightful book, *Altered Inheritance*, Françoise Baylis examines how Glybera, a gene therapy drug that treated pancreatitis, was introduced to the world. She notes "in 2015 when the drug went on the market, it became the world's most expensive drug, at approximately one million US dollars for a one-time dose. Though safe and effective, this gene therapy proved to be a commercial failure, due to limited demand and its high cost."[13] After those who were willing and

able to pay for Glybera received their dose, its license had expired, and the drug had eventually disappeared.[14]

Only those with the economic means to afford Glybera were able to receive the treatment. It was made inaccessible to most of the world's population given its enormous price tag. While not all medical treatments remain equally inaccessible, Glybera exposes the competitive, profit-driven marketing schemes that often underlie pharmaceutical companies. Our neoliberal outlook leads to inaccessibility and inequality. There are many medical treatments and vaccines without a high price tag that are largely inaccessible to much of the world's population.[15]

While it is true that Glybera, along with the drugs that pharmaceutical companies manufacture, are instances of therapy, as opposed to enhancements, this reinforces the problem further. If we cannot make life-saving therapy accessible, especially the kind that prevent a multitude of physical pain and that are arguably a human right,[16] the prospect of making genetic enhancements accessible to everyone seems very low. While the same problem of inaccessibility could apply to therapeutic genetic changes, the focus here is primarily on enhancements.

There is reason to think that using CRISPR-Cas9 to edit the germline will not be cheap, at least not at first.[17] Mark Trusheim, a researcher at MIT who examines the economics of biomedical innovation, has suggested the "cost [of CRISPR-Cas9] isn't coming down."[18] The unfortunate reality is that "the price point that yields the highest profits is always higher than the price point accessible to everyone."[19] While determining the cost of germline enhancements remains difficult, especially given the moratorium we are in, and the years it would take to make this process at least somewhat safe, it is reasonable to assume that if and when such technology became available, its expensive price will make a lot of people lose out. More recently, the COVID-19 pandemic has clearly shown the inequalities around the world considering the global distribution of vaccines.

Wealthy nations have hoarded the vaccine supply while depriving other low- and middle-income countries (LMICs) from accessing vaccines.

Hence, the prospect of those in LMICs accessing gene-enhancing technology would seem to be significantly less. This is especially true given the already existing economic disparities among countries, along with the staggering amounts of poverty and lack of adequate healthcare. The United Nations estimates that 8.6% of the global population or 730 million people live in extreme poverty,[20] while the World Bank and World Health Organization report that at least half of the world's population lack basic health services.[21]

Introducing gene-editing technology is likely to lead to inaccessibility. This, as noted by many scholars, will probably lead to the exacerbation of existing inequalities. As stated by Lee M. Silver and corroborated by Françoise Baylis,

> The use of genetic enhancement could greatly increase the gap between the "haves" and the "have-nots" in the world. A gap between classes within societies may emerge initially. But when the cost of reprogenetics drops, as the costs of computers and telecommunications did, it could become affordable to the majority in Western and other industrialised countries…When this happens, the economic and social advantages that wealthy countries maintain could be expanded into a genetic advantage. And the gap between wealthy and poor nations could widen further with each generation until all common heritage disappears. A severed humanity might be the ultimate legacy of unfettered global capitalism.[22]

Although we cannot be certain that this will occur, it does not seem unreasonable. In support of premise *iii*, it seems likely that heritable genetic enhancements will yield significant harms and only produce some good for a limited few. While introducing heritable genetic enhancements may benefit those rich enough to receive (i.e., yield minimal good), its reward is very minimal compared to the collateral harm that will be done to those who cannot access it (i.e., likely most of the world).

2.2 An Objection

In his book, *Enhancing Evolution: The Ethical Case for Making Better People*, John Harris provides a response to a similar concern. He says,

> Imagine if someone had said (and been heeded) that we should not invest in books and in literacy and education because it was expensive and elitist and could not be provided for all, or that we should not do so until it could be provided for all…The same went for the founding of schools. Now in much of the world all children have some schooling, and university education is in many countries available for a majority of those who can (and who wish to) benefit. [23]

Harris' analogical response is clear. The inability to make enhancements equally accessible to everyone is not a sufficient reason to stop its implementation. Perhaps like education, we will eventually arrive at a moment when it becomes available to most of the world's population.

However, while education has certainly become more attainable in recent years, suggesting that education is accessible in the contemporary world is mistaken. The UN reported over 55% of children worldwide "lacked minimum proficiency in reading and mathematics in 2015." Although Harris' example was meant to be analogical, it is important to note that access to "education" and "literacy" is not available for the majority of children around the world.

Harris assumes that the toleration of inaccessibility and inequality will only be a temporary matter. That is, given enough time, the playing field will be levelled, and gene-editing technology (similar to education) will become accessible. There is reason, however, to remain skeptical of this assumption. If for so many years we cannot make education available to the world, it seems unlikely that we will make an expensive technology also available to the world. The most probable case here is that introducing heritable genetic enhancements will exacerbate the existing inequalities that our world faces. While of course, we cannot be certain of what will happen, it does seem at least more likely that heritable genetic enhancements will yield significant harms and produce minimal good, given the problem of inaccessibility.

3. Conclusion

If indeed it is true that heritable genetic enhancements will yield significant harms and produce minimal good, we now have moral reason not to pursue heritable genetic enhancements. The concerns around accessibility and inequality give us reason to think this is true. I have tried to show that although we cannot be certain about the outcomes of its implementation, yet we have reason to support premise *iii*, and conclusion *iv* that follows.

There are indeed more concerns regarding the implementation of heritable genetic enhancements, but that space could not allow. For instance, concerns around eugenics, human dignity, consent of future generations, "playing God," and more. Yet I remained focused on what I think is perhaps the strongest claim against heritable genetic enhancements. I consider this argument to hold a lot of force because it is grounded in an accurate assessment of the world's existing inequalities. That is, there is good reason to suppose that we would fail to introduce this technology fairly. If our world faced minimal injustices, then we can assume that implementing heritable genetic enhancements may be introduced accessibly—yet the evidence shows otherwise.

Notes

[1] "China Jails 'Gene-Edited Babies' Scientist for Three Years," BBC News (BBC, December 30, 2019), https://www.bbc.com/news/world-asia-china-50944461.

[2] Eric S. Lander, et al., "Adopt a Moratorium on Heritable Genome Editing," *Nature* 567, no. 7747 (2019): pp. 165-168, https://doi.org/10.1038/d41586-019-00726-5.

[3] "The Nobel Prize in Chemistry 2020," NobelPrize.org, accessed April 1, 2021, https://www.nobelprize.org/prizes/chemistry/2020/summary/.

[4] Although it was not entirely successful.

[5] Françoise Baylis et al., "Human Germline and Heritable Genome Editing: The Global Policy Landscape," *The CRISPR Journal* 3, no. 5 (January 2020): pp. 370, https://doi.org/10.1089/crispr.2020.0082.

[6] Ibid.

[7] Non-heritable therapeutic changes are currently being researched and tried.

[8] Eric S. Lander, et al., "Adopt a Moratorium on Heritable Genome Editing," pp. 165-168.

[9] Some of these proponents include John Harris and Nick Bostrom.

[10] R. Alta Charo, "Who's Afraid of the Big Bad (Germline Editing) Wolf?," *Perspectives in Biology and Medicine* 63, no. 1 (2020): pp. 93-100, https://doi.org/10.1353/pbm.2020.0007.

[11] Ibid., 97.

[12] National Academies of Sciences, "Second International Summit on Human Genome Editing: Continuing the Global Discussion: Proceedings of a Workshop–in Brief," The National Academies Press, January 10, 2019, https://www.nap.edu/catalog/25343/second-international-summit-on-human-genome-editing-continuing-the-global-discussion#:~:text=On%20November%2027%2D29%2C%202018,the%20University%20of%20Hong%20Kong.

[13] Francoise Baylis, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing* (Cambridge, MA: Harvard University Press, 2019), 26.

[14] Kelly Crowe, "The Million-Dollar Drug," CBC News (CBC/Radio Canada, November 17, 2018), https://newsinteractives.cbc.ca/longform/glybera.

[15] Overview - SDG Indicators," United Nations, accessed April 21, 2021, https://unstats.un.org/sdgs/report/2019/Overview/.

[16] See Article 25 of the Universal Declaration of Human Rights.

[17] Jim Kozubek, "Who Will Pay for CRISPR?," STAT, June 23, 2017, https://www.statnews.com/2017/06/26/crispr-insurance-companies-pay/.

[18] Ibid.

[19] Alison Irvine, "Paying for CRISPR Cures: The Economics of Genetic Therapies," Innovative Genomics Institute (IGI), December 18, 2019, https://innovativegenomics.org/blog/paying-for-crispr-cures/.

[20] "Overview - SDG Indicators," United Nations, accessed April 21, 2021, https://unstats.un.org/sdgs/report/2019/Overview/.

[21] "World Bank and WHO: Half the World Lacks Access to Essential Health Services, 100 Million Still Pushed into Extreme Poverty Because of Health Expenses," World Health Organization, December 13, 2017, https://www.who.int/news/item/13-12-2017-world-bank-and-who-half-the-world-lacks-access-to-essential-health-services-100-million-still-pushed-into-extreme-poverty-because-of-health-expenses.

[22] Francoise Baylis, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing*, 67.

[23] John Harris, *Enhancing Evolution: The Ethical Case for Making Better People*, 14.

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4

AESTHETIC MODIFICATIONS

1. Introduction

Heritable human genome editing creates the possibility of modifying the genes of future generations for aesthetic reasons. That is, changing their DNA in ways we prefer or in ways we think are beautiful. Some examples include changes to hair texture, hair colour, eye colour, skin colour, freckles, and so on. This chapter considers these heritable genetic changes and assesses whether they are morally permissible.

Johnathan Anomaly refers to these genetic changes as "aesthetic enhancements."[1] This conceptualization, he thinks, is justifiable if we assume the standards of beauty among humans are universal and if aesthetic traits produce greater overall health.[2] To make future generations more beautiful, on this view, would be to give them a better and healthier life. There is reason, however, to suppose the above assumptions are not well established. Anomaly admits that our standards of beauty can be "mostly relative"[3] and that the positive correlation between beauty and health is "quite loose."[4] While there may be a few physical traits that are widely considered to be aesthetically pleasing, such as facial symmetry, and there may be a loose correlation between beauty and health, referring to aesthetic changes as "enhancements" seems exaggerated.

Suppose two prospective parents decided to give their child hazel-coloured eyes and curly hair. Presumably, a child with hazel eyes and curly hair would not be improved or enhanced in any relevant way. While the parents might have a child that aligns more with their own aesthetic

preferences, and the child might be appreciated by some for their hazel eyes and curly hair, the changes seem largely insignificant.

All things considered, genetic enhancements improve future generations in relevant ways, for instance by increasing their cognitive abilities or making them physically stronger. Aesthetic changes, however, seem to be more a matter of taste. Some individuals may prefer hazel eyes, others may not. Some may think curly hair is more attractive while others may not. Regardless of what colour our eyes are, or how curly our hair is, it does not make us any better or worse. Hence, there should be hesitancy to conceptualize aesthetics changes as "enhancements." While this suggestion is not essential to the moral arguments that follow, I will hold on to the view that these genetic changes are neutral.

While remaining committed to the *neutral-ness* of aesthetic genetic changes, I would like to offer a tentative proposal that we should not engage in altering the genes of future generations for aesthetic reasons. The moral concerns lie in the intentions and consequences of aesthetic changes, rather than the changes themselves. I examine two concerns that support my position. The first considers a commonly cited concern of these genetic changes inspiring a kind of eugenics, one that is discriminatory and prejudicial. The second considers *the principle of reasonable imposition* which argues that *unless we can reasonably assume that the intended genetic change will be well-received by future generations, we should refrain from changing their genomes for aesthetic reasons*.

2. Background

Classifying aesthetic changes as "neutral" seems appropriate because they neither enhance nor debilitate future generations. John Harris suggests similar changes are "morally neutral," because "no reasonable person thinks it could be *morally* better to have one colour of hair rather than

another, nor for that matter to be one gender rather than another."[5] This seems true. It would not be a vice to have hazel eyes and curly hair, nor a virtue. These traits would not make us moral exemplars nor moral villains.

Heritable aesthetic changes to the genome are neutral because they neither enhance nor debilitate, and because they do not make us any morally better or worse. This, for Harris, may give grounds for their permissibility. He says, "so long as the feature is neutral (neither better not worse to be) then if it is not wrong to be such a person, not harmful, undignified, disadvantaged in any serious way, then it cannot be bad or wrong to create a person with those features."[6] While Harris might perceive the *neutral-ness* of aesthetic changes as a reason for their permissibility, others might perceive it as a reason to the contrary. If it truly does not matter what observable traits future generations will inherit, why bother changing them at all?

A child without aesthetic changes to their genes has an equal chance of living a flourishing life as one with the changes. Therefore, to make these changes seems superfluous and unnecessary. At worst, aesthetic changes can even cause harm if its resources can be allocated to support more relevant and pressing concerns. The appeal of aesthetic genetic changes is similar to other aesthetic concerns we engage in. We change our physical appearance in many ways for a variety of reasons. Heritable aesthetic changes provide an additional tool to make us look more the way we want to. Let us turn to the moral concerns of heritable aesthetic changes.

3. Liberal Eugenics

The term "eugenics" often recalls the horrific beliefs and practices of the Nazis in the 20th century. Their eugenic policies were based on discriminatory, racist, and dehumanizing ideologies that led to mass sterilization and mass extermination. It was somehow believed they could improve the

gene pool by eliminating undesirable traits; a kind of eugenics that is condemned by all reasonable people.

For contemporary advocates of eugenics, however, they notably distinguish themselves from the eugenics of the past. Nicholas Agar, for instance, defends *liberal eugenics*,[7] a kind of eugenics that is premised on reproductive freedom and choice, rather than authoritarian rule.[8] He bases this view on the presumption that parents should be allowed to change the genetic characteristics of their children. Rather than the state deciding what changes should be sought, Agar proposes that liberal eugenics leaves the choice at the discretion of the parents. This, among other suggestions, could remove the fear and worries of engaging in previous and atrocious forms of eugenics.

Liberal eugenics allows prospective parents to raise their children in accordance with their own preferences and ideas about what constitutes a flourishing life. Furthermore, unlike the eugenics of the past, liberal eugenics allows prospective parents to make informed decisions with a contemporary understanding of hereditary. That is, with a modern and progressive view of genes and heredity. For Agar, this would largely prevent individuals from making the "hopelessly wrong" choices made in the past that were based on pseudoscientific claims.[9]

While liberal eugenics may be less coercive and more subtle than the eugenics we find in history, it is still morally concerning. Allowing prospective parents to decide the aesthetic traits of their offspring, rather than the state, does not eliminate the possibility of discrimination. Parents can be as equally racist, sexist, discriminatory, and prejudicial as national or government-driven eugenic practices. It is not difficult to imagine prospective parents wanting to give their children fairer skin because they possess prejudice against dark skin. Or perhaps they might want to give their children blue eyes and blonde hair because they show partiality towards those features. These

views can be held implicitly or subconsciously; what may be thought of as a "preference" can be mischaracterized as discrimination or prejudice.

While the social consequences of these practices, over a long time, are difficult to predict, it remains feasible that these actions can lead to a discriminatory form of eugenics. Parental choice regarding aesthetic trait selection can reduce or eliminate characteristics that are held in lower regard. This is especially alarming in societies with homogenous preferences, as parents might be collectively encouraged to produce a particular kind of child.

To a similar claim, Agar says,

> When one chooses a mate one is often also choosing what kind of person will contribute genes to one's children. We accept that racist people can refuse to have children with members of a race they despise because we think that who one is attracted to and repelled by is beyond state regulation. Our negative judgements about their characters do not lead us to force them into relationships with people for whom they claim no attraction. By analogy, perhaps no moral reason could be sufficiently strong to justify the state's intruding on individuals' eugenic choices.[10]

Our libertarian freedoms, it seems, necessitate that we tolerate the choices of partner selection, even if they are racist. For Agar, the same logic applies to the choices we make within a liberal eugenic framework.[11]

This is a good point to consider and was similarly made by John Harris in chapter 2, as an argument in favour of genetic enhancements. Unless there are immediate and significant harms that will result from our genetic modifications of future generations, our reproductive liberties should allow us to engage in gene editing. These are the consequences of our autonomy.

This argument, however, suggests a socio-political stance in favour of genetic modifications rather than a moral one. There are many actions that our libertarian freedoms do not restrict but are nonetheless morally wrong. Lying to a friend or breaking promises are actions that, although the state should not intervene and criminalize, are immoral.[12] Although racist individuals

possess the liberty to choose or not choose members of a particular race as mates, their racist ideas are morally wrong.

Consequently, changing the aesthetic traits of future generations in ways motivated by discriminatory and racist views of the world also seems wrong, and obviously so. Even if libertarian societies may eventually permit heritable genetic changes in the future, citing our individual autonomy, it would not make such actions *morally* permissible.[13] This is what is meant when the concerns lie in the *intentions* and *consequences* of aesthetic changes, rather than the changes themselves. While the actual aesthetic traits of future generations that are determined by racist parents are not inherently problematic as such, the processes, consequences, and motivations behind them can be.

While I do think aesthetic changes pose a risk great enough to completely restrict its use at a governmental level, I will leave this issue aside for the conclusion. Thus far, we have looked at the aesthetic changes that may be motivated by discriminatory, though perhaps unconscious, motives. It seems clear these are morally wrong. Yet what about the aesthetic changes that are made with sincere and good intentions by prospective parents? It seems possible that some people can prefer curly hair over straight hair, without necessarily believing that straight hair is somehow *inferior*. Others can prefer blue eyes, without thinking they are somehow *superior* to the other eye colours. Perhaps these are less likely to lead to problematic outcomes. What should we make of these?

4. The Principle of Reasonable Imposition

Assuming it can be done safely and accessibly, there are some genetic changes that we can reasonably assume future generations would deem *desirable*. For instance, eliminating debilitating diseases like sickle cell anemia, cystic fibrosis, Huntington's disease, and so on. It is difficult to

imagine future generations inheriting genetic disorders that cause varying amounts of physical pain. We can reasonably assume that preventing these diseases will be beneficial for future generations.

Comparatively, the prospect of parents editing their children's genome for aesthetic reasons does not seem to be a *clear* desirable change. Whereas the role of eliminating genetic diseases is to prevent suffering, the role of aesthetic changes, though harder to identify, is perhaps for children to look better, or to meet parental standards of beauty. Future generations, however, may feel ambivalent towards the changes that were made on their behalf. Although they may come to appreciate the changes to their hair, eyes, ears, etc., they might also consider them futile and undesirable.

Hence, proceeding with the following *principle of reasonable imposition* is recommended: *unless we can reasonably assume that the intended genetic change will be well-received by future generations, we should refrain from changing their genomes for aesthetic reasons*. It would be strange to make genetic changes to future generations that will not clearly benefit them. Anything outside clear beneficial changes seems unreasonable.

Since obtaining the consent of future generations is not possible, as they do not yet exist, there is epistemic uncertainty concerning what changes they might enjoy or deem desirable. Whether they would enjoy blue eyes over hazel eyes or curly hair over straight hair seems impossible to determine. Given the uncertainty we find ourselves in, refraining from making these changes seems like a reasonable and precautionary approach. It is probably best not to introduce an aesthetic change, especially if we are unsure or hesitant about whether the change will be well-received.

The exception, of course, is if we find good reasons to make aesthetic changes. Perhaps prospective parents might think some changes will allow their children to live better lives. Aesthetic genetic changes, however, are largely concerned with appearance, as they tend to be non-enhancing adjustments to our physical traits. Because these seem to be a matter of taste, we cannot be confident that these aesthetic changes will be desirable for future generations.

Some might be inclined to suggest that even if the aesthetic changes are not well-received by future generations, they are nonetheless "neutral." That is, they are not actually being harmed by the change. Hence, aesthetic changes should remain morally unproblematic. While the actual change is likely neutral and would not disadvantage the recipients in serious ways, it might still be better, practically speaking, to not impose these changes.

If future generations wish to look a certain way when they become adults, they can do so on their own terms. They can make changes to their appearance in many ways, albeit in ways they enjoy. This might mean getting cosmetic surgery, dyeing their hair a different colour, or getting coloured contact lenses. This way, not only can we respect their autonomy by allowing them to make these choices for themselves, but we can also avoid imposing a change that they may conceive as undesirable.

While it is true that parents make a lot of decisions for their children, until a certain age, such as what school they will be enrolled in, what clothes they will wear, or what food they will eat, choosing their aesthetic traits seems to be both unnecessary and forceful because we cannot convincingly say that "it is for their own good" as many of these other decisions are. A better alternative would seem to allow the children to grow up and make their own decisions regarding their appearance, as opposed to parents imposing their own preferences on the child.

While the technology for genetic engineering is new and ongoing, perhaps one day it will be possible to make aesthetic changes to the somatic cells of adults, resulting in non-heritable genetic changes. That is, adults could change their hair colour by editing their own genes, without the consequences of passing on the changes to future generations. This would give everyone the choice of making their own genetic changes, as opposed to simply inheriting them. While this needs rigorous amounts of scientific research and trials, it remains, at least, conceptually possible and a better alternative.

Furthermore, these aesthetic changes can even lead to a kind of hyperagency or hyper-parenting, as proposed by Michael Sandel in his article *The Case Against Perfection*. Regarding genetic engineering, he says: "The deeper danger is that they represent a kind of hyperagency—a Promethean aspiration to remake nature, including human nature, to serve our purposes and satisfy our desires."[14] While Sandel has proposed this idea in the context of genetic enhancements, it is nonetheless applicable to aesthetic changes as well.

Prospective parents engaging in modifying the genes of their children for aesthetic reasons seems largely trivial. It seems to be picking and choosing the physical qualities of future generations as though we are customizing our favourite clothing item. Intuitively, this kind of reshaping and molding of nature for aesthetic reasons seems wrong, even if the changes are "neutral." Being concerned with unimportant, nonessential, characteristics appears to be a frivolous pursuit.

This argument, indeed, may not be as potent as previously identified concerns. This is understandable as others might possess a different intuitive hunch about heritable aesthetic changes. The main concerns, however, stand apart from this one. It is primarily the concerns

around the epistemic uncertainty of what traits future generations will find desirable, along with practical considerations that should give us hesitancy about heritable aesthetic changes.

5. Conclusion

This chapter considered various ethical concerns about modifying the genes of future generations for aesthetics reasons. While these genetic changes are *neutral*, because they neither enhance nor debilitate and because they do not make us any morally better or worse, my tentative proposal is that we should not engage in them.

This position was supported by the dangers of liberal eugenics and the principle of reasonable imposition. Aesthetic changes, even within a liberal eugenic framework do not eliminate the possibility of prospective parents choosing traits motivated by discriminatory and prejudicial views. Furthermore, even if prospective parents assumed good intentions, they are still morally problematic due to the uncertainty of preferences of future generations, relevant practical concerns, and, for some, the triviality of aesthetic changes.

While it may be a reference to personal autonomy that eventually paves the way for prospective parents to choose the aesthetic traits of their children, it need not be that way. Within the context of human gene editing, Françoise Baylis has proposed "a relational understanding of autonomy" as a viable alternative to a traditional—highly individualistic—understanding of autonomy.[15] This view,

> explicitly embraces the notion of persons as interdependent relational beings and recognizes that autonomy is, in important respects, a product of social relations…people are socially, politically, and economically situated beings who develop their interests and values in conversation and interaction with others. This relational understanding of autonomy draws our attention to the less familiar, but no less important, concepts of neighborliness, reciprocity, social solidarity, and community—concepts that underpin any clear commitment to social justice.[16]

This conceptualization of autonomy seems to be more suitable to move forward with human gene editing, especially for aesthetic changes. While we are each entitled to our own freedoms, it is important to understand how our choices and decisions impact those around us, and how aesthetic changes can have significant collective consequences.

Notes

[1] Jonathan Anomaly, *Creating Future People: The Ethics of Genetic Enhancement* (New York, NY: Routledge, 2020), 40.

[2] Ibid., 44.

[3] Ibid., 41.

[4] Ibid., 49.

[5] John Harris, *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton, NJ: Princeton University Press, 2010), 146.

[6] Ibid., 144.

[7] While Agar defends liberal eugenics within the context of human enhancement (genetic and otherwise), the application of this framework is relevant to the discussion of aesthetic modifications, even without explicit mention.

[8] Nicholas Agar, *Liberal Eugenics: In Defence of Human Enhancement* (Malden, MA: Blackwell Publishing, 2005), 5.

[9] Ibid., 7.

[10] Ibid., 15.

[11] For Agar, he does allow for the state or a private organization to intervene as a third party to potentially stop these changes motivated by discrimination (page 15). However, it seems, implementing this may lead back to state-controlled eugenics or some variant that limits the freedom of prospective parents. This seems problematic. A further challenge may be that it is unfeasible to for a third party to determine the motivations behind parental choice. It would be difficult to assess which genetic changes are correctly motivated and those that are not.

[12] Generally speaking. There may be some circumstances where lying or breaking promises are permissible, for instance, if the Gestapo are at your door asking if you are hiding any Jews, etc.

[13] Jürgen Habermas has long since predicted this tension between our libertarian freedoms and our engagement with biotechnology in *The Future of Human Nature*.

[14] Michael Sandel, "The Case Against Perfection," The Atlantic (Atlantic Media Company, April 1, 2004), https://www.theatlantic.com/magazine/archive/2004/04/the-case-against-perfection/302927/.

[15] Francoise Baylis, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing* (Cambridge, MA: Harvard University Press, 2019), 184.

[16] Ibid.

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5

A CASE STUDY

Introduction

Thus far this thesis has considered and deliberated on the moral permissibility of heritable non-therapeutic genome editing. Chapters 2 and 3 considered reasons for and against heritable genetic enhancements and suggested that even if they can be considered as good things, there is no positive moral obligation to pursue them. Furthermore, concerns around inaccessibility give us moral reason to not engage in them. Chapter 4 considered aesthetic modifications and concluded that while they can be characterized as "neutral," concerns around liberal eugenics and parental imposition give us moral reason (at least tentatively) not to pursue them.

The goal of this chapter is to collectively consider the possible good and negative outcomes that heritable non-therapeutic human genome editing can bring. These are mostly drawn from previous chapters. Once both good and negative outcomes are considered, I conclude with a suggestion that when we weigh them against each other, the negatives outweigh the positives. That is, we have minimal benefits to gain and a lot to lose if we decide to pursue heritable non-therapeutic human genome editing. Given this, a precautionary approach toward these genetic changes seems justifiable.

To illustrate the positive and negative outcomes, I use a hypothetical case study of prospective parents that wish to introduce heritable non-therapeutic genetic changes for their future child. While this chapter presents a different approach than previous chapters, it nonetheless fits into my overall argument that the case against heritable non-therapeutic human genome editing is

stronger than the case in favour. It does, however, embody a supplemental rather than an essential argument to my overall position.

Case Study

Prospective parents, Alex and Blake, believe all parents have an obligation to give their children a good life. Motivated by this duty, they take a trip to *Baby n' Design*, a private genetic screening and genome-editing health centre. Upon arrival, they are kindly greeted by the receptionist and asked to wait for the doctor. When Dr. M enters the room, she greets Alex and Blake and takes them into a private consultation room. "The process is simple," Dr. M explains, "we create one embryo using *in vitro* fertilization, run a genetic diagnosis on the embryo, and make any changes to the genome that you wish before implanting. We have had a 99% success rate with our methods." Alex and Blake express their interest and ask, "what genetic changes can we make?" Dr. M gives them a catalogue that lists the wide range of possible changes. "Other than screening and removing the disease-causing gene mutations, *Baby n' Design* can make changes to eye colour, hair texture, height, intelligence, and even athleticism." Alex and Blake are amazed and decide to continue with the procedure. After a few days, Dr. M creates an embryo with Alex and Blake's reproductive cells retrieved in the first visit. Once the genetic screening results come in, Alex and Blake are invited for a second visit. Dr. M ensures them that the genetic screening suggests their child is healthy and will not inherit any genetic disease. Dr. M then asks "what changes would you like to make?" Alex and Blake respond, "After much deliberation, we have decided that we want a muscular, intelligent, brown-eyed, curly-haired child. Is that possible?" Dr. M nods her head with a smile and says, "yes, of course."

The Positives

Given our current stage of gene-editing technology and the global moratorium opposing heritable human genome editing, the above scenario remains only hypothetical.[1] It does seem, however, that altering the genes of future generations in safe and accurate ways is within reach. Perhaps it is only a matter of time before the science, along with our laws and policies, make the above scenario a feasible possibility. This case study assumes that it is possible and safe to accurately introduce heritable non-therapeutic genetic changes in future generations. If and when this happens, it is important to consider the goods this technology can bring.

Firstly, if Alex and Blake were allowed to create their muscular, intelligent, brown-eyed, curly-haired child, their overall autonomy and reproductive liberty would seem to be respected. It seems reasonable to suppose, as predicted by German philosopher Jürgen Habermas, that it will be a reference to personal autonomy that advances, and perhaps encourages, our engagement with genetic engineering.[2] Autonomy, at least in many libertarian societies, has become a revered principle that has become very powerful, particularly in the field of bioethics.

The "right to live," "the right to die," and the "right to choose" have become foundational to our approach to medical assistance in dying, abortion, and the patient-physician relationship. The connection can also be applied to heritable genome editing. It appears prospective parents, like Alex and Blake, should have the freedom to alter their own genes and those of their children, without constraints from the government or society primarily because they possess the right to. Notwithstanding the potential dangers of this freedom, respecting reproductive liberties seems like a good thing.

Secondly, Alex and Blake, along with other parents that decide to make similar changes, will make future generations physically stronger. That is, they will provide them with the genetic

predisposition for more muscle. They will be able to possess more muscle than they otherwise would have had, had it not been for the genetic change. While there *may* be a point where being too strong can be detrimental to someone's well-being (i.e., everything around them is too fragile, they easily injure or intimidate those around them, they are negatively considered to be a social outlier or outcast, etc.), being stronger is generally considered to be a good thing. In fact, we go to the gym and try to remain strong to maintain good health, prevent injury, and increase our age expectancy. Hence, being stronger is a good thing.

Thirdly, Alex and Blake will make future generations smarter, perhaps through an increase in memory and cognitive capabilities. This obviously seems like a good thing, as higher intelligence can help humans with many different tasks. It can help society progress and solve many of the complex problems that our world faces and will face in the future. Many of us attend grade school for a significant portion of our lives and eventually go on to pursue further studies, often for the sake of becoming smarter and often to help the world to become a better place.

It is important to note that the degree of goodness that "being stronger" or "being smarter" is depends precisely on *how much* stronger and *how much* smarter humans can be with genetic intervention. How much stronger will the genetically altered human be compared to the non-genetically altered human? Or how much smarter will the genetically altered human be compared to the non-genetically altered human? This is difficult to determine as no formal research studies have been conducted that show the difference. We are required to speculate. Perhaps we should be two-fold, tenfold, or even twenty-fold smarter and stronger.

One thing that is not speculative, however, is that our traits are not only determined by our genes, but by our environment as well. As Françoise Baylis suggests,

> The myth that we are our genes (the embrace of genetic determinism) can be seen most obviously in the seemingly endless stream of media reports on the "gene for this" and the

> "gene for that," which invariably fail to explain that all traits are multifactorial. Our traits are the result of a complex web of environmental and genetic causes and influences—where the environmental causes and influences include everything that happens from conception onward that isn't genetic…a child who is born to tall parents will be short if starved…Similarly, while there is a clear genetic component to intelligence, there are also important environmental contributions, which is why societies invest in public education, and why parents with additional resources sometimes hire private tutors or pay for private schooling.[3]

This all suggests that while being stronger and smarter through genetic intervention is possible, it is not a guarantee that it will contribute in significant ways. It is possible for the non-genetically altered human to be smarter and stronger than the genetically altered human, given the differences in environment.

The commitment of Alex and Blake to introduce curly hair and brown eyes in their does not clearly contribute to a good thing, other than their wishes being fulfilled. Perhaps the child, and other children that inherit similar changes, will come to appreciate and enjoy the aesthetic changes that their parents have introduced. This is difficult (or impossible), however, to determine, although the possibility remains. Now that we have considered some of the positives of the above case study, let us consider the negative components.

The Negatives

Firstly, it would become possible for parents to introduce heritable non-therapeutic genetic changes with ill-intent. Alex and Blake may want a muscular, intelligent, brown-eyed, curly-haired child because they think the child will be attractive, beautiful, or more likely to succeed (although these traits do not guarantee a successful or flourishing life). It may also be possible for prospective parents to introduce these same genetic changes with intentions that are motivated by racism and discrimination. Although intentions may be difficult to determine from an outsider's perspective, the unfortunate possibility remains.

Even without prospective parents being motivated by ill-intent, a harmful kind of liberal eugenics can be espoused (which was discussed at length in previous chapters). History shows us the dangers of deliberately selecting and choosing our genetic traits, especially when it is done to improve the human species. This kind of heritable human genome editing makes liberal eugenics a real possibility that can, especially over a long time, profoundly and negatively affect the future gene pool.

Secondly, there will likely be a problem associated with inaccessibility. Besides Alex and Blake, will other prospective parents in their nation and around the world possess the same ability to engage in heritable non-therapeutic genome editing? As discussed in previous chapters, perhaps this technology will not be cheap and will only be available to those in higher socio-economic positions. The risk of introducing this technology in inaccessible ways is costly.

As Françoise Baylis has suggested, it can lead to a gap between the "haves" and the "have-nots."[4] I am inclined to argue that from a global perspective, the gap between the "haves" and "have-nots" already exists, given the high rates of poverty, lack of education, lack of adequate health care, and other injustices that our world currently faces. Introducing genetic changes that make *only some* humans smarter and stronger would only exacerbate the existing inequalities that exist. In short, this can lead to very negative consequences.

Thirdly, heritable non-therapeutic genetic changes introduce the danger of unreasonable parental imposition, by untenably imposing our own preferences on future generations. This is especially problematic because of the unpredictability of how future generations will respond when they realize their eye colour, hair texture, intelligence, and physical strength have been deliberately chosen by their parents. These responses can vary. Some might learn to enjoy them

and appreciate them. Others may feel ambivalent toward the changes or even feel betrayed. Some may consider a few changes desirable while others as undesirable.

Whereas there may be a strong case for eliminating debilitating genetic disorders like Huntington's disease, the same degree of confidence cannot be extended to non-therapeutic changes. It is too risky to impose these genetic changes on future generations given the negative outcomes that can ensure. Additionally, it is better from a practical perspective, to allow future generations to make their own choices regarding their physical appearance and their genes. They can grow to eventually make changes that they prefer and deem as desirable.

Weighing the Positives and the Negatives

Assuming it were safe and within our power to introduce heritable non-therapeutic genetic changes, we have considered both positive and negative outcomes that can happen as a result. The positive outcomes include the respect of autonomy, along with making human beings stronger and smarter (although to what degree cannot be determined). The negative outcomes included the possibility of these genetic changes being motivated ill-intent and leading to liberal eugenics, exacerbating existing inequalities by becoming inaccessible, and the risk of untenably imposing our own preferences on future generations.

While opinions on this may differ, it appears to me that these negative concerns far outweigh the positives that heritable non-therapeutic genetic changes can bring. Even if it is possible to become stronger and smarter tenfold, the gain is minor in comparison to the risks associated with implementing them. There is a lot that can go wrong with its implementation. Additionally, considering the environmental factors that contribute to our traits, there is no guarantee that we will reach any considerable degree of intelligence and strength with genetic intervention. It could be very minimal and therefore certainly not worth the risk.

While we may be suppressing the autonomy of prospective parents, it comes at a reasonable cost. A precautionary approach that limits heritable non-therapeutic genetic changes seems justifiable if we can prevent the dangers posed by these edits. Risking the possibility of non-therapeutic genome editing leading to eugenics, inaccessibility, and untenable parental imposition is not worth the potential reward.

Notes

[1] Eric S. Lander, et al., "Adopt a Moratorium on Heritable Genome Editing," *Nature* 567, no. 7747 (2019): pp. 165-168, https://doi.org/10.1038/d41586-019-00726-5.

[2] See Jürgen Habermas' *The Future of Human Nature* (Cambridge, UK: Polity, 2016).

[3] Baylis Françoise, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing* (Cambridge, MA: Harvard University Press, 2019), 66.

[4] Ibid., 67.

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CONCLUSION

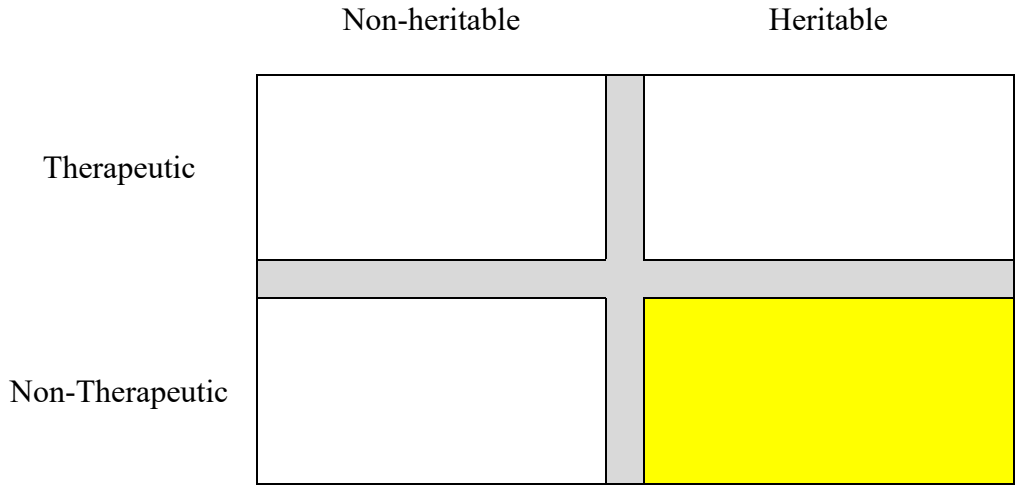
Given the pace at which human gene-editing technology is progressing, it is reasonable to suppose that "the next big thing" is around the corner. Our moral deliberation on its permissibility should happen sooner rather than later. I hope this project has benefitted you, the reader, in developing your moral position on heritable non-therapeutic human genome editing (i.e., genetic changes that seek to alter the genes of future generations for enhancement and aesthetic reasons). While there are good arguments that support heritable non-therapeutic human genome editing, I have tried to show that the case against heritable non-therapeutic human genome editing is stronger than the case in favour.

In summary, Chapter 1 considered the current framework used to deliberate on the permissibility of human genome editing. I argued that although the current framework (making use of the treatment-enhancement and somatic-germline distinctions) is under attack, it is nonetheless feasible with some added revisions. Chapter 2 considered two arguments in favour of heritable genetic *enhancements* and argued that they do not amount to a moral obligation to pursue them, even if they are identified as good things.

Chapter 3 served as a continuation to the previous chapter and considered arguments against heritable genetic *enhancements*. I argued that because heritable genetic enhancements will likely yield significant harms and produce minimal good, we have moral reason not to pursue them. Chapter 4 considered heritable *aesthetic* genetic changes and argued that while aesthetic genetic changes can be characterized as neutral (because they do not make us better or worse),

concerns around liberal eugenics and parental imposition give us moral reason (at least tentatively) to not implement them. Chapter 5 considered a case study about prospective parents and their desire to bear a child with non-therapeutic genetic changes. I suggested that when we collectively consider the possible good and negative outcomes of heritable non-therapeutic human genome editing, we have little to gain and a lot to lose.

This thesis only focused on one section within the revised framework. Only what is highlighted in yellow (see below) can be properly characterized as heritable non-therapeutic human genome editing.



There is still more that needs to be considered regarding this topic, for instance, *heritable therapeutic* genetic changes. These are genetic changes that seek to alter the genes of future generations to eliminate genetic disorders like Huntington's, sickle cell anemia, muscular dystrophy, and so on. These have been alluded to throughout the project but used only as comparative examples rather than as topics of consideration.

Presumably, while heritable therapeutic human genome editing may seem less contentious than their non-therapeutic counterpart, they also present ethical challenges. In fact, considerations regarding eugenics and inaccessibility can also be applied to heritable therapeutic genetic changes.

For instance, Carol Padden and Jacqueline Humphries have suggested in *Who Goes First? Deaf People and CRISPR Germline Editing* that because genetic deafness is commonly considered to be pathogenic (i.e., a disease), we might be committed to removing these genes in the future.[1] Yet they suggest, contrary to this common perception, that genetic deafness is not a "serious disease" and should instead be preserved to retain human diversity.[2] We must therefore be careful in navigating the thorny task of deciding what counts as "genetic disease" and what does not.

The problem of accessibility too can also be applied to heritable therapeutic genetic changes. If only a select few individuals can access CRISPR-Cas9 to eliminate genetic disorders, there is presumably a moral problem here. Other moral issues within the revised work include whether it would be immoral to not introduce genetic changes that would eliminate disease-causing gene mutations in future generations. That is, would we have an obligation to remove genetic disorders? Furthermore, while non-heritable genetic changes tend to be less morally contentious because they do not get passed on to future generations, they also contain interesting moral dilemmas, and so too do the "grey" genetic changes that are both therapeutic and non-therapeutic components. Needless to say, this thesis has only scratched the surface.

I would, however, like to end on important consideration that has been underlying the thesis, namely, that human genome editing is *instrumental* as it can be used for both good and bad outcomes. This reveals that the primary concern with human genome editing has less to do with the actual gene-editing technology but more with ourselves. The worry is not CRISPR-Cas9, but how we use CRISPR-Cas9. Perhaps in an ideal world, we could implement this technology solely in good ways that avoid harmful outcomes. Yet on an honest assessment of ourselves and the state of our world, there is reason to doubt that we can do that successfully.

Notes

[1] Carol Padden and Jacqueline Humphries, “Who Goes First? Deaf People and CRISPR Germline Editing,” *Perspectives in Biology and Medicine* 63, no. 1 (2020): pp. 54-65, https://doi.org/10.1353/pbm.2020.0004.

[2] Ibid.

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