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Human Genome Editing: Making People Better or Making Better People?

Almost all medical advancements are, on the surface, absolute positives. To argue against a technology that saves lives or reduces disability can seem, and often is, ridiculous and illogical. Perhaps the most notable of all recent medical advancements is CRISPR, one of several treatments with the ability to alter the genome of an individual, effectively removing the very root of a specific genetic disease. CRISPR-Cas9, which is currently the most popular genome editing technology, is composed of two major parts: an enzyme (Cas9) that acts as a pair of DNA-splicing scissors, and a piece of RNA that binds to the stretch of DNA to be altered, allowing the enzyme to splice the correct segment. Once the sequence is ‘deleted,’ the body will recognize this damage and repair the DNA, replacing the disease-causing nucleotide sequence with a healthy counterpart (Sanger). This new, healthy DNA will then be expressed in the individual, essentially curing their disease.

Like most medical treatments, CRISPR is not without risks. There is potential that the wrong gene could be spliced, leaving the patient with the diseased sequence and possibly causing mutations in other parts of their genome. Researchers have estimated that CRISPR fails or malfunctions 15% of the time, but the true scope and impact of errors in genome editing is difficult to estimate. These mistakes range from entirely inconsequential to potentially

debilitating. There are also few studies looking at the long-term impacts of CRISPR treatment, a major driving force behind its current lack of FDA approval.

Despite the risks, this technology has been used successfully in patients with a variety of genetic diseases, including sickle cell anemia and Huntington's disease. Patients once unable to live a normal life, or even hope for a normal lifespan, have had their lives completely altered by CRISPR treatment. Today, CRISPR is only available in clinical trials, but could be FDA-approved and opened to a wider market before 2024. Though the drug must go through the same extensive testing and monitoring as others pharmaceuticals, its unique DNA-altering properties have given way to further restrictions (IGI).

CRISPR is generally used in somatic cells, limiting its genetic alterations to a single individual. Germline editing, which is widely banned and condemned globally, involves the editing of reproductive cells, creating alterations that are passed down to future generations. It can also be used in embryonic cells, reducing a developing embryo's likelihood of developing certain diseases. In the US, doctors and scientists are currently barred from this type of editing for fear of the creation of "designer babies"- embryos altered to have specific traits, ranging from a reduced cancer risk to a certain hair color. This is the same fear behind restrictions on germline editing. The line between medical necessity and personal convenience or desire is often blurry, adding a layer of ethical complexity that many believe overrules the healing power of CRISPR.

Despite the potential risks, popular opinion currently remains in favor of therapeutic genome editing, and simultaneously strongly opposed to the creation of "designer babies" through germline or embryonic alterations (Bergman). While this restriction is reasonable, its enforcement has proven challenging even in the most nascent stages of CRISPR development.

For example, researchers in Guangzhou, China, have used the technology to manipulate the myostatin of beagles, creating abnormally muscular dogs.

This could easily be applied to humans to create individuals (or generations) with a kind of superhuman strength. The mere idea of creating a subset of humanity with a genetically engineered advantage over others is clearly problematic - at what point does this engineering stop? Will the relative success of individuals become fully dependent on the extent of their genetic alterations? What about those unable to access the technology? Currently, the scientific community has decided that these heavy questions are better left unanswered than explored with genome editing. To edit a genome is to edit what makes us human; taking this practice too far puts the human race in danger of losing our humanity.

Experiments such as the beagles in the Guangzhou lab show that, even with restrictions, regulations upon genetic engineering are largely ineffective. In 2018, Dr. He, a Chinese doctor, blatantly ignored both national and international restrictions on embryonic gene editing when he altered the genes of twin girls to increase their HIV resistance. The uproar in the scientific community was swift and unyielding: Dr. He was stripped of his medical license and sentenced to prison. Little is known about the girls' health, but He's experiments raised further questions about human genetic engineering. Dr. He's work made it clear that even the most stringent of restrictions are not sufficient to dissuade the use of CRISPR technology in the creation of designer babies. China's rules regarding germline editing are similarly strict as the US, creating the possibility of such rules being disregarded globally. The driving force behind these experiments was the heavy stigmatization of HIV in China, and the girls' father's fear of potential social ostracization (CBS).

Again, this raises the issue of the blurry line between medical necessity and personal preference. It was not known if these girls would contract HIV, and certainly not known if it would be impactful on their lives. The only driving force behind the alteration was the fear of social ostracization. If scientists were able to uncover a gene causing autism, would this be something to “fix?” What about other, subjectively disadvantageous personality traits or physical characteristics, such as imperfect dental structure or albinism? The expansion of CRISPR from life-saving applications to vanity-serving purposes appears almost unstoppable, given the indistinguishably blurry boundaries between the two. Humans have a long history of stepping over the boundaries we create for ourselves, a pattern which should not be ignored in the application of CRISPR. At the start of the Manhattan Project, the US stated they would use nuclear explosives only in case of a strike from the Axis powers. Clearly, this did not prove to be true. Humans are excellent at convincing themselves that something is necessary at the expense of preexisting regulations.

In the near future it is not hard to imagine that the uber-wealthy would adopt genome editing technology as a way to further distinguish themselves from the normal population, whether through superior disease resistance or improved physical characteristics. The cost of CRISPR treatment, once widely available, will likely be far too expensive for any American of average wealth, let alone those living in third world countries. This could create a divide in which the wealthy people of society suffer from less disease while the poor remain unchanged. Over time, this technology would likely become cheaper as production costs decrease, but providing access to the lab and medical facilities necessary would be prohibitively difficult for millions globally (Boston University). The division of humanity into the disease-free and the diseased is a frightening prospect, and certainly not impossible with the rise of genome editing.

All of these doomsday possibilities must be weighed against the concrete benefits of genome editing. Diseases that once posed a terrifying threat to an individual's being can be cured with just one infusion. Despite these benefits, the ethical implications with genome editing technologies are far too vast to be ignored. Currently, a global moratorium on CRISPR research and production should be considered until the implications can be weighed completely and thoroughly. Rushing headlong into a new era of healthcare without taking time to fully understand its effects on both individuals and humanity could have irreversible consequences. Before CRISPR becomes commercially available, the scientific and global community must decide whether the technology will be used in making people better or making better people, and if this distinction truly exists.

Works Cited

Bergman, Mary Todd. "Harvard Researchers Share Views on Future, Ethics of Gene Editing." *Harvard Gazette*, Harvard Gazette, 8 Nov. 2022, <https://news.harvard.edu/gazette/story/2019/01/perspectives-on-gene-editing/>.

CRISPR Ethics Reading - Boston University.

<https://www.bu.edu/khc/files/2018/10/CRISPR-Ethics-reading.pdf>.

"Playing God: 'We Are in the Midst of a Genetic Revolution.'" *CBS News*, CBS Interactive, <https://www.cbsnews.com/news/playing-god-crispr-dna-genetic-ethics/>.

Sanger. "What Is CRISPR-Cas9?" *@Yourgenome · Science Website*, 8 Feb. 2022, <https://www.yourgenome.org/facts/what-is-crispr-cas9/>.

"When Will CRISPR Cures Be Available?" *Innovative Genomics Institute (IGI)*, 24 Oct. 2022, <https://innovativegenomics.org/news/when-crispr-cures/>.