Title

An Ethical Look at CRISPR

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A Queer, Disabled, and Normative Look at CRISPR

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Abstract: CRISPR-CAS9 gene editing allows for precise editing of genetic structures. While this technology has focused mostly on gene therapy meant to help those with chronic illnesses, human embryos were edited in 2018. The ethical concerns of this use of technology lead to the discussion of whether we should limit the use of this technology to prevent devastating social consequences.

INTRODUCTION

This work is a partial fulfillment of the ENGR184 course, and attempts to apply native feminism and critical queer theory to a case study's use of technology and its wider consequences, and aims to discuss what would happen assuming this technology is limitlessly applied while our society and its norms remain the same.

In 2018, He Jiankui announced that he had successfully gene-edited 2 twin baby girls. Immediately after the announcement, the world was set ablaze with critique, commentary and condemnation, with many proclaiming that his actions needed serious punishment. The Chinese government then sentenced him to 3 years in jail. Over time, his actions would fade into obscurity, with the 2 girls, Lulu and Nana, leaving the prying gaze of the world as suddenly as they had entered, and CRISPR and gene-editing in humans became less significant as a world issue.

More recently, gene-therapies for cancer patients and others with chronic illnesses have become available, and either had positive results or were fully adopted by the FDA. While there is much talk as to the medical applications and enhancements that could lie in this technology, a less discussed issue is about how this technology unfairly treats queer and disabled identities, and could be used as a tool to erase both of them from our society, and could further divide the populations that remain.

METHODS

In researching this topic, I looked at how this technology would affect the disabled, the queer, and the ordinary person through case studies, testimonials, medical journals and my interpolation based off of the lines of logic set by all of the above, with the positive impacts of this technology coming from a source stating various medical breakthroughs. In contrast, the negative impacts come from articles stating medical consequences and speculation from others. This was to measure the positive and negative influence that could be set in place by the mass implementation of this technology without radically changing our societal rules and systems.

When I researched this topic from the lens of the disabled, there were 2 radical opinions or stances from various groups of the disabled. In one case study, over 200 people suffering from Duchenne Muscular Dystrophy wrote to the scientist responsible for the genetic editing of human embryos asking for a genetic therapy for their condition, bringing a man once condemned for his actions against genetics back into the lab. In another case study, 2 women, one with cystic fibrosis, and another with a form of syndactyly, argued against this technology, stating that their disability has allowed them to access another level of self-care, improving some aspects of their lives over those without disabilities. As such, the issue stems from whether the disabled can decide whether they want to partake in genetic therapy, and the reaction that society would have towards the disabled once this technology becomes mainstream. As it stands currently, the medical model would remain the same, showcasing their disabilities as pure limitations, while the societal model would shift significantly, with the general population moving the societal barrier from hostile architecture to a new medical treatment. As such, the dilemma for CRISPR gene-editing lies in the erasure of many of the disabled who use the technology, and more extreme further mistreatment of those who continue to live with their disabilities either due to personal wishes or the lack of treatment development to those who live with something that occurs in a small percentage of the population. With the full adoption of this new technology, it is likely that, in the near future, the disabled may be eugenically cleansed from society.

The implications of CRISPR are arguably even worse for those who identify as queer. This stems from the thought behind the “gay gene,” which was the product of a study from 1993, which showed a correlation between the genetic marker xq28 in gay men. While this result was never replicated in further experimentation, many online forums, news stories, and people continue to believe so. This comes not long after the history of homosexuality being known as a psychiatric illness until the 1970s, and only being removed from the International Classification of diseases as late as 1992. As such, it is extremely likely for anti-queer outside influences to renew their push for a new and improved way to medically treat the queer. From my research, while those who suffer from disabilities are rather divided by this new technology, the queer uniformly agree that the development of CRISPR would lead to their identities being reaffirmed as an illness as it has been historically, and would eventually lead to the loss of their acceptance.

Lastly, I noted that the emergence of CRISPR gene-editing would also negatively affect people who consider themselves to not be queer or disabled. First and foremost, scientists have made mention of CRISPR’s damaging effects on a cell’s ability to fight cancer, and speculate that this technique could do more damage than expected. Beyond the purely medical negative side effects, one notable ethical area that could be affected is reproductive rights, where parents could fold to societal pressure to use genome editing on their children before their birth. This would lead to issues behind the representation of minorities and the disabled, as minorities could have their desirable physical traits and genetic material used without their consent, and in return could find themselves pressured to gene-edit their children to fit in better with societal standards. This would lead to a reduction in genetic diversity, and reinforce hegemonic domains of the ideal body. Another ethical concern would be the question of equal access to this technology, as our capitalistic systems would make low-income families who would likely wish to have access to this technology unable to afford treatment, which in turn could keep them in poverty if there is a social divide between those who have been gene-edited and those who are not. On the other side of the coin, those who are wealthy would potentially have unprecedented access to CRISPR, and would be able to give both themselves and their families an unprecedented advantage, further reinforcing settler colonialism by letting the rich achieve a look or trait that minorities used to only have. This technology would also prove itself to reinforce the triad by making companies specializing in gene therapy extremely rich, and give insurance companies unprecedented power in that they can determine the traits and fates of people both before and after they are born. Lastly, those who would take out a loan to use gene-therapy to give themselves better traits would find that their body would be a property of the bank, which would further reinforce a capitalistic dystopia defined by body dysmorphia and debt while removing the idea that your body belongs to you only.

The positives of CRISPR techniques would be the potential for chronic diseases such as cancer to be treated and potentially cured before it would even begin. It could also make us humans resistant to microbes and STDs as they grow resistances to conventional treatments. It would also be able to treat genetic diseases such as sickle-cell anemia by removing the mutation that caused it in the first place. However, as research into genetic markers grows, leaving the development of these techniques unchecked will lead to more consequences than affirmations.

RESULTS AND INTERPRETATION

The main results of this study show that every marginalized and mainstream community has some or total resistance to the mass implementation of this new medical technology in our current system, with the main concerns being reproductive rights violations, the breakdown of the societal model of disability, and would eventually lead to those identifying as queer or disabled to silently be snuffed out as a way of getting all of society to conform with traditional normative ways of living. There would also be the paradox of using a non-science reason to force people back to the 2 gender norm. As such, the mass implementation of CRISPR gene editing would lead to extreme consequences for everyone, and the development of this technology should be relegated to chronic illnesses that lead to either the loss in quality of life, or death, or a disability where a majority of people afflicted wish to not live with it anymore.

CONCLUSIONS

From the research above, the mass implementation of CRISPR is divisive among the disabled community, unanimously hated by the queer community and minorities, and somewhat divisive among ordinary people, with a bias towards limiting the implementation of CRISPR. The mass implementation of CRISPR without limitations or change in our power structures would practically erase the disabled, the queer, and other minorities, while allowing for white colonialism to allow the masses to use the genetic material of minorities to give themselves traits they consider favorable, and cost everyone who remains genetic diversity, personhood, and sovereignty. As such, this technology should be used with extreme care, and should be limited to helping recover from chronic illnesses or extreme disabilities that negatively impact daily life, and should only be used with express consent personally from the person receiving said treatment. This treatment must also be available at no cost to the patient, and for health insurance to be unable to deny this treatment as essential care to ensure that hegemonic systems of class do not lead to further inequality. International law should also be passed to ensure greater consequences so that the case study from He Jiankui never happens again.

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