Designer Babies: Evaluating the Ethics of Human Gene Editing

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Abstract: The development of CRISPR-Cas9, the world's most advanced gene editing tool, continues to astonish scientific and medical communities with its unbelievable potential to eradicate thousands of diseases and save countless lives. The concept of editing a person's DNA does however raise concerns on the relatedness of gene therapies to eugenicist practices. Following the births of genetically modified babies in China, the World Health Organization and other global health commissions faced the challenge of creating regulatory frameworks to monitor and advise countries on the safe and ethical use of gene therapies. This case study examines the ethical implications of CRISPR-Cas9 therapies, its potential to cure disease and the risks associated with the application and commercialization of gene-editing technologies, for exacerbating inequality and discrimination.

Introduction

In late November 2018, A biophysicist named He Jiankui[1] wanted to recruit couples consisting of a man diagnosed as a carrier of HIV and a woman who was not a known carrier for a potential study. After working with Baihualin, a Beijing AIDS advocacy group, Jiankui recruited participants and gave them new hope to have children protected from HIV by using CRISPR-Cas9 technology to edit their embryos, claiming that the potential babies "would be resistant to HIV" (Cohen 2019, n.p.). Nine months after the trial first started, twin baby girls known as Lulu and Nana, to protect their identities, were born. These trials for editing HIV-related genes in embryos were only the beginning of the endless possibilities for the editing of countless other traits. The news of Lulu and Nana's births, the world's first genetically modified babies, unleashed debate within the scientific community and left many people questioning the ethical implications of the scientific innovation known as CRISPR-Cas9.

The Birth of CRISPR-Cas9

As the 2020 winner of the Nobel Prize in Chemistry, CRISPR-Cas9 (or CRISPR for short) and its creators Dr. Jenifer Doudna and Dr. Emmanuelle Charpentier received the most prestigious form of recognition for their outstanding contributions to science and for the vast potential of CRISPR to "effectively change the genetic makeup of any organism and fix a near infinite number of problems" related to genetic disorders and other diseases (Moon 2021, n.p.). The tool's name is an acronym standing for 'clustered regularly interspaced short palindromic repeats,' and Cas9 refers to the enzyme used to cut various DNA segments (Saey 2017, n.p.). CRISPR-Cas9 technology allows a researcher to locate specific genes on any organism's DNA and modify

[1] To prevent confusion, He Jiankui will hereafter be referred to as "Jiankui", his given name, rather than "He" his family name.

targeted genes, giving scientists the potential to "cure genetic defects, eradicate diseases, and even end the organ transplant shortage" (Lewis 2015, n.p.). Even though the possibilities of gene-editing technologies seem to bring endless promise for the future of medicine and science, many questions on the ethics and equity of genetic research and treatments still arise.

Hoping to tackle the ethical concerns surrounding CRISPR, two international commissions, one created by The National Academies of Science, Engineering and Medicine (NASEM), and another by the World Health Organization (WHO), set out to "create a global regulatory framework" and to verify the science behind CRISPR applications for the future responsible editing of human genes (Isaacson 2021, 329). Although the scientific community seems hopeful in the eventual regular implementation of CRISPR in gene therapies, opening the door to editing DNA could also mean enabling practices rooted in eugenics, classism, racism, and gender discrimination. For instance, genetic research often capitalizes off of extremely vulnerable subjects and patients in order to create life-changing medical treatments. Specifically, in Jiankui's research, recruited couples had to face the stigma and health issues that surround both being HIV positive and not being able to have children. In the name of expanding the field of genetic research, clinical trials—requiring the participation of sick individuals—have historically demonstrated exclusionary and discriminatory practices, which have led to the distrust of medical professionals and genetic researchers.

Informed Consent in Medical Research

Analyzing historical cases of ethical violations within medical research can inform future steps regarding cases like CRISPR. An infamous example demonstrating how unethical research disproportionately affects minority groups is the case of Henrietta Lacks. In 1951, Henrietta Lacks, a 31-year-old Black woman, was diagnosed with advanced stage cervical cancer. Doctors and scientists treating Lacks at the Johns Hopkins University Hospital then went on to clone and use samples of Lacks' cancerous cells, labeling them as "HeLa" cells, to research and develop major medical innovations for cancer treatments and other research fields (Azamer Butler 2021, n.p.). Despite continued use of HeLa cells today, Lacks' family was never compensated for the contribution of her cells, nor did Lacks give informed consent for the use of her cancerous cells by today's consent standards (Azamer Butler 2021, n.p.).

Now, patients have the right to refuse or authorize an intervention or action by a practitioner, but this right can only be "effectively exercised if the patient possesses enough information to enable an intelligent choice" (Beauchamp 2011, 516). Legislation establishing parameters for informed consent first began in 1972, long after Lacks' passing, with critical cases such as *Canterbury v. Spence,* in which a surgeon left a patient paralyzed after failing to inform the patient of the surgery's possible risk of paralysis (Sutherland 2020). This decision led to huge legislative changes regarding medical practices in America. At the time of Lacks' hospitalization, little to no procedures on obtaining consent from patients existed in the U.S. (Johns Hopkins Medicine, n.p.). Decades after Lacks' first diagnosis and treatments, her family plans to sue a biotechnology company that holds stakes in HeLa cells for the "unconsented cloning of biological material" (Azamer Butler 2021, n.p.).

As the case of Henrietta Lacks illustrates, medical and genetic research fields often fail to receive informed consent and thus perpetuate the exploitation of women, and particularly women of color. Years of reform in medical practices have strengthened the definition and application of informed consent; however, when dealing with vulnerable populations such as sick individuals, people of low socioeconomic standing, minority groups, and children, many medical professionals

and scientists still do not address the unequal power dynamic between themselves and the patients or communities that they serve. Lack of education and understanding around medical practices and scientific terms as well as intrinsic trust in physicians often prevents patients from questioning their healthcare providers, leading to miscommunication and even malpractice cases. *The Journal of Medical Ethics* explains the nature of the relationship between informed consent and unequal power dynamics in clinical research and states that research subjects and medical patients often have "excessive trust that medical investigators aim primarily to benefit them" and that this assumption awards researchers even more power over their patients (Eyal 2014, 439). Dealing with vulnerable subjects allows for manipulation, even if unintentional, on the part of the physician or researcher.

These risks are very evident when looking at the case of Lulu and Nana's births. Even though the participants involved in Jianku's research had the relevant informed consent protocols explained to them, their vulnerability and emotional attachment to the study may have influenced their decisions (Cohen 2019, n.p.). In some cases, concerns about medical exploitation have incited serious reform of medical ethics policies. In other instances, the lack of ethical guidelines and policies have allowed for the overt abuse of vulnerable populations and added to the exploitative structure of modern medical and scientific research systems.

Eugenics and Scientific Racism

In the past, power structures have used genetic research to promote eugenicist ideals of whiteness and masculinity as more genetically favorable traits, and these ideals quickly transcended from mere theory to actual practices. Examples of these abusive practices include the forced sterilization[2] of women of color during the 20th century in the U.S. (Human Rights Watch 2011, n.p.). One of the first documented instances of legal forced sterilization occurred in 1899 with the sterilization of inmates at an Indiana prison (Manjeshwar 2020, n.p.). Other examples include the "coerced sterilization of nearly one-third of the women in Puerto Rico [from 1930 to 1970], when government officials claimed that Puerto Rico's economy would benefit from a reduced population" and the Supreme Court decision to authorize the mandatory sterilization of inmates in mental institutions in Virginia in the *Buck v. Bell* case in 1927 (Manjeshwar 2020, n.p.).

Eugenicist ideals also have ties to other groundbreaking medical innovations such as birth control and additional forms of contraception. Margaret Sanger, a nurse who eventually became one of the founders of Planned Parenthood, established in 1921, faced strong opposition in her mission of empowering women with reproductive agency and making contraception a widely accepted concept. Sanger claimed to direct most of her efforts towards marginalized communities because "poverty and limited access to health care made women [of color] especially vulnerable to the effects of unplanned pregnancy," but her intentions were driven by racist ideals (Latson 2016, n.p.). Sanger worked with several eugenicist organizations in distributing and enforcing birth control methods to poor, predominantly Black communities and was vocal in her support of eugenicist ideals. In a 1921 article, Sanger wrote that "the most urgent problem today is how to limit and discourage the over-fertility of the mentally and physically defective" (Latson 2016, n.p.).

The aforementioned atrocities illustrate the historical prevalence of eugenicist principles, including eradicating "undesirable" traits from the population, and bring to light the disproportionate effects of abusive and exploitative genetic research and medical practices on

[2] Forced sterilization is defined by *Human Rights Watch* as an involuntary process or act that renders an individual incapable of sexual reproduction (2011).

women, racial and ethnic minorities, and people of low socioeconomic status (National Human Genome Research Institute 2021, n.p.). In addition to harming marginalized groups, genetic research methodologies seem to "privilege certain values which might be regarded as masculine rather than feminine" (Chadwick 2009, 12) Eugenicist theories also typically favor masculine traits along with stereotypical "white" traits (Chadwick 2009, 12). Eugenicists regarded these traits as superior and aimed to replicate them in the population via selective breeding, by only having children with individuals that expressed these traits (Goering 2014). In research settings these 'preferences' may manifest as biases and can jeopardize the validity of studies.

Just as traits of masculinity and whiteness are considered favorable, certain traits associated with genetic disorders are considered unfavorable. Genomic screening technologies that can predict risks for genetic disorders before insemination also propose the concept of altering genetic traits to suit the preferences of the potential parents (National Human Genome Research Institute 2021, n.p.). Therefore, clients of certain fertility clinics may have the opportunity to select a preferred embryo based on the expected traits of that embryo. The possible screening of "embryos for behavioral, psychosocial and intellectual traits would be reminiscent of the history of eugenics in its attempt to eliminate certain individuals" (National Human Genome Research Institute 2021, n.p.). These advancements in genetic testing allow for the detection of several congenital conditions and abnormalities and allow parents to choose to abort in many instances of abnormalities. For example, "in the U.S., a prenatal diagnosis of Down's Syndrome results in abortion approximately two-thirds of the time" (Isaacson 2021, 337). Although some aspects of genetic testing methods may seem biased and selective, decisions surrounding choosing to obtain prenatal diagnoses or choosing to abort are extremely complex, and factors influencing parent's decisions include; financial costs, emotional strain, support systems etc. (Burke 2021, n.p.). Therefore, innovations in prenatal diagnosis illustrate the huge impact that these screening technologies can have in allowing for the early detection and treatment of birth defects, bettering patient outcomes, and transforming the way that maternal and prenatal health are studied and practiced.

CRISPR Therapies

When analyzing the ethics of the applications of CRISPR-based therapies, innumerable opportunities to prevent, treat and even eradicate disease, greatly complicate the attitudes surrounding gene-editing. Some examples of clinical trials that have taken place involving CRISPR include the treatments of "multiple myeloma, esophageal, lung, prostate, and bladder cancers, melanoma, leukemia, HIV-1, gastrointestinal infection, β-thalassemia and sickle cell disease" and in China at least 86 people have had their DNA edited in clinical trials as of May 2018 (Brokowski and Adli 2019, 2). These diseases, many of which are life-threatening, each affect thousands of people globally, and innovations in their treatments could potentially save countless lives and substantially alleviate their suffering.

The main controversy with genome editing concerns germline editing. Germline editing refers to the modification of the "DNA of human eggs, sperm or early-stage embryos so that the cells in resulting children will carry the edited trait" and be able to pass this trait down to their descendants (Isaacson 2021, 336). However, the application of CRISPR on somatic cells, non-germline cells, has received plenty of support from the scientific community along with the public and has already been used in clinical trials in the U.S.

Victoria Gray, a 34-year-old Black woman from Mississippi with sickle cell disease was the first person in the U.S. to have her somatic cells treated with a CRISPR based therapy. Sickle

cell disease impacts "more than 4 million people worldwide and about 90 thousand people in the U.S," the vast majority of which are of Sub-Saharan African descent (Isaacson 2021, 246). After having dealt with years of debilitating pain caused by her disease, nine months after receiving an injection of her CRISPR modified cells, Victoria Gray no longer experienced the shocks of pain associated with the disease and testing confirmed that "81 percent of her bone marrow was producing healthy blood cells, meaning that the gene edits were sustained" (Isaacson 2021, 247).

Similarly, new innovations in the treatment and prevention of cancer using CRISPR technologies have generated a lot of support, particularly because of the tool's speed and efficiency in diagnosing different cancers. The process involves CRISPR editing immune cells that can "hunt down and attack" cancer, but the effectiveness in reducing and slowing the growth of tumors still requires much more research (National Cancer Institute 2020, n.p.).

CRISPR has also generated immense hope for the treatment of Alzheimer's disease. As the sixth leading cause of death in the U.S., Alzheimer's disease demands new and effective innovations in treatments. Alzheimer's disease is a progressive and irreversible brain disorder "characterized by a deterioration of attention, memory, and personality" which affects an estimated 5.3 million Americans, and dramatically increases in prevalence for elderly individuals (Sarafino and Smith 2022, 359). Researchers in a Canadian lab have conducted experiments using CRISPR on brain tissues to prevent Alzheimer's, and their research suggests that potential CRISPR treatments will "reduce Alzheimer's likelihood" by 4 times (Prabhune 2021, n.p.).

Although many of these treatments require much more research and many more clinical trials before any patients will have access to them, the mere existence of CRISPR provides countless families hope for treating devastating genetic diseases. The treatment of diseases such as sickle cell disease, which disproportionately affect Black populations, also highlights a way for the medical community to move towards the more equitable medical treatment of a historically underserved population, but the tremendous cost associated with gene editing may counter these equity building initiatives by exacerbating the disparities between rich and poor.

Patenting CRISPR

The miraculous opportunities for the treatments of disease using CRISPR therapies do not come cheap. Gene-editing therapies cost millions of dollars and it is unrealistic for current healthcare systems to provide these therapies to the average patient. The massive expenses related to CRISPR therapies have encouraged the commercialization and patenting of the technology. From an ethical standpoint, commercializing CRISPR supports exclusionary practices, by making treatments unaffordable and perpetuating unproductive competitiveness between research institutions. The federal law enacted in 1980, the Bayh–Dole Act, enables creators of CRISPR to both patent and profit from their technology despite using federally funded research (Markel 2013, n.p.). In many cases the opportunity for profit can help universities to generate income for further research as well as add a financial incentive for scientists and researchers to create breakthrough scientific innovations (Markel 2013, n.p.). Converse to the intentions of this act, patents pose the risk of decreasing the integrity of scientific research initiatives. "The obvious danger of increasing the focus on commercialization is that educational institutions will view scientific research as a path to profit" and these potential finance-driven pressures may discourage collaboration with researchers from competing institutions (Sherkow 2016, 173). As seen in the development of other genetic interventions, the work of scientists and genetic researchers does not always result from altruism or service for the greater good, but can often be attributed to an entrepreneurial pursuit of profit or recognition. When looking at the atmosphere within research-oriented spaces such as elite

universities, researchers themselves acknowledge that "academic culture has become much more receptive to exclusive rights and the commercial exploitation of scientific knowledge" (Feeney et al 2021, 6). These motivations can also lead to less transparency with the public, along with disregard for the ethical implications of their research (Feeney et al 2021, 6).

The crisis of unaffordable healthcare in the U.S. highlights the dangers that patenting vital drugs and therapies pose for Americans, particularly groups of low socioeconomic standing. We can compare patenting CRISPR technologies with the patenting of another medical innovation that has changed millions of people's lives: insulin. People affected by diabetes, particularly Type 1 diabetes, cannot make their own insulin and therefore need to take or inject it to avoid dangerous blood sugar levels. Hundreds of thousands of people die from diabetes related causes every year, yet purchasing insulin or related drugs costs hundreds of dollars per month without health insurance (Irving 2021). The first patent of insulin, held by the University of Toronto in 1923, "gave drug companies the right to manufacture it and patent any improvements," as well as dictate the prices of newly patented versions of insulin (Johns Hopkins Medicine 2015, n.p.). Similarly, the patenting of CRISPR will allow pharmaceutical companies to determine the pricing of CRISPR therapies, likely making them inaccessible to most of the population.

Designer Babies

As one of the most controversial topics that arises when contemplating ethics of gene-editing therapies, "designer babies" may seem like an idea from a science fiction novel, yet some forms of this concept are already a reality. A fertility startup in New Jersey known as Genomic Prediction, established in 2017, has analyzed embryo samples for in vitro fertilization[3] and allows customers to select the "embryo to implant based on the characteristics they want in their child" (Isaacson 2021, 361). Aside from being able to select an embryo free from health issues or genetic disorders, in as little as 10 years, this technology may allow customers to select embryos based on predictions of sex, IQ, height and physical strength (Isaacson 2021). Past eugenicist ideologies illustrate that, traits linked with whiteness, masculinity, and western ideals take precedence as more favorable. Many cultures and societies have an overwhelming preference for male babies, revealing the innate discriminatory nature of the concept of designer babies. Globally, especially in Asia and North Africa, there is an observable preference for sons over daughters, where cultural, religious, and economic practices perpetuate overt patriarchy (Le and Nguyen 2022). A 2018 survey, conducted by an independent research company, Gallup, also revealed a slight preference for male babies among Americans (Lardieri 2018). When asked if they could only have one child, 36% of the participants answered that they would prefer a male child, 28% answered that they would prefer a female child, and the remaining participants claimed no preference or opinion (Lardieri 2018). These preferences illustrate how the possible ability to choose the gender of a potential child through gene editing, could lead to an increase in male births and a decrease in female births, creating a gender imbalance in the population.

The enormous cost associated with designer babies and gene-editing therapies worsen inequity as these types of therapies would only be available to very wealthy individuals. If only the rich can access these resources, "[germline] editing could exacerbate inequality and even permanently encode it into our species" (Isaacson 2021, 362). Even with all the potential risks that come with gene-editing, the argument for the moral obligation of humans to alleviate as much

[3] *The Oxford Dictionary* defines in vitro fertilization (IVF) as a medical procedure whereby an egg is fertilized by sperm in a test tube or elsewhere outside the body (2022).

suffering as possible, and ensure the welfare of our future descendants, adds to the complexity of the case for CRISPR. During an interview, Dr. Jennifer Doudna, the inventor of CRISPR, was asked about her opinion on the use of CRISPR to edit embryos and responded as follows:

> I started to hear from people with genetic diseases in their family. A mother who told me that her infant son was diagnosed with a neurodegenerative disease, caused by a sporadic rare mutation. She sent me a picture of this little boy. He was this adorable little baby, he was bald, in his little carrier and so cute. I have a son and my heart just broke. What would you do as a mother? You see your child and he's beautiful, he's perfect and you know he's going to suffer from this horrible disease and there's nothing you can do about it. It's horrible. Getting exposed to that, getting to know some of these people, it's not abstract any more, it's very personal. And you think, if there were a way to help these people, we should do it. It would be wrong not to (Devlin 2017, n.p.).

The NASEM and WHO Commissions

Although by U.S Law research involving human embryos cannot be federally funded, the NASEM and WHO commissions on CRISPR initiated the process of outlining guidelines on the ethical implications of gene-editing embryos and the permitted applications of CRISPR technologies (Brokowski and Adli 2020, 2). In 2020, NASEM published a comprehensive 200-page report on Heritable Human Genome Editing (NASEM Report) discussing their deliberations on the future applications of CRISPR in editing human embryos (Brokowski and Adli 2020). Other deliberations on CRISPR took place in 2018 on Capitol Hill with Jenifer Doudna and eight U.S. senators. The senators "were electrified by the potential [treatments for] sickle-cell, and for other debilitating single-gene diseases such as Huntington's and Tay-Sachs, and about what it meant for sustainable healthcare" (Isaacson 2021, 329).

The NASEM Committees consist of experts in the fields of science, engineering, medicine, and other fields, whose goals include conducting investigations to provide objective advice to inform policies on various ethical issues and scientific innovations. Appointments to these committees are based on expertise, perspectives, objectivity, diversity, and Academy membership in order to ensure equitable and informed decision making (NASEM 2020). While formulating the NASEM Report in 2020, the commission consisted of eighteen experts from some of the most prestigious institutions around the world, gathering to deliberate on the ethics of editing the human germline as well as CRISPR's implications for the U.S. and abroad (Davies et al. 2020). The WHO Commission also formulated their own report to provide a global regulatory framework for the use of gene editing, but Margaret Hamburg, co-chair of the WHO Commission, "conceded that this [framework] was unlikely to prevent countries from crafting their own rules" (Isaacson 2021, 329). Hamburg also predicted that varying regulatory standards could lead to "genetic tourism," where wealthy individuals looking for genetic enhancements could "travel to the countries that offer them" (Isaacson 2021, 329).

Some critics of He Jiankui believe that Jiankui wanted to create a clinic "located in China or Thailand, to attract elite customers from other countries" (Regalado 2019, n.p.). The concept of genetic tourism emphasizes the innate exclusionary qualities of germline editing on a global scale, but also leaves unanswered questions on how permitting such practices would affect countries with socialized medicine. If some germline edits are deemed medically necessary by a specific country's medical board, would countries with socialized medicine make germline edits accessible to the public, and how would these permissions perpetuate health gaps in less developed countries

with less access to health care in general? Nuances in legal and medical systems outside of the U.S. highlight the difficulties the NASEM and WHO committees may face in regulating the use of CRISPR, particularly in the case of Jiankui.

He Jiankui

After a lengthy investigation by the People's Court of Shenzhen, China, Jiankui and two of his collaborators were convicted for conducting "illegal medical practices" and Jiankui was sentenced to three years in prison as well as fined $429,000 (Normile 2019, n.p.). The court found the collective guilty of "forging ethical review documents and [conning] doctors into unknowingly implanting gene-edited embryos into two women," one of whom was the mother of the infamous twins, Lulu and Nana (Normile 2019, n.p.). The charge of "illegal medical practice" comes from the fact that Jiankui and his accomplices did not break any Chinese laws surrounding the violations of ethical regulations but rather under Article 336 of the *Criminal Law of Chinese People's Republic* they conducted "medical activities without authorization" or licensing (Lei and Qiu 2020, n.p.). This charge means that in China if Jiankui had only obtained a license for his practice, he would not face any jail time. (Lei and Qiu 2020, n.p.). Jiankui's initial medical ethics approval application outlined its goals for his application of CRISPR in stating that "[these trials] are going to be a great scientific and medical achievement ever since the IVF technology, which was awarded the Nobel Prize in 2010, and will also bring hope to numerous genetic disease patients" (Cohen 2019, n.p.). Just after the first news of Lulu and Nana's births broke, Jennifer Doudna recalls Jiankui's reaction to the public response to the news of the babies saying that "[Jiankui] seemed surprised by the immediate, intense flood of attention and mounting criticism. It was bizarre. He seemed so naïve" (Cohen 2019, n.p.). When asked about the trials Jiankui exclaimed that he felt confident that he complied with all the ethical and procedural criteria. Although Jiankui's reaction may be one of perceived innocence, it still illustrates a large disconnect between his intentions and the impact of his actions, which could have grave repercussions for the future of genetic research and more importantly, for the human race.

Conclusion

After hearing the news of Jiankui's clinical trials, the NASEM Committee began working on their comprehensive report to fully analyze the dangers and potential of human gene editing as a medical innovation. At the end of the NASEM deliberations, the commission concluded that "human heritable genome editing, the modification of the germline with the goal of creating a new person who could potentially transfer the genomic edit to future generations, would be permissible under certain conditions" (Brokowski and Adli 2020, 2). The conditions on which the conclusion stand remain unclear, aside from the need for more research on the topic. Their conclusions imply that as more research on editing the human germline is conducted, the legal use of CRISPR on human embryos may become a reality. Regardless of the potential legality of germline therapies, the question of whether to prioritize the prevention of medical discrimination and neo-eugenicist practices or to alleviate the suffering of millions worldwide remains.

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