

The Benefits and Harms of Gene Editing

On November 26, 2018, the scientific community woke up to what some called an ethical disaster. He Jiankui, a Chinese biophysicist, announced that he had successfully edited the genes of a set of twins – two girls named Lulu and Nana, born to a father with HIV. He claimed to have disabled the CCR5 gene, which assists HIV in entering cells. The experiment was rudimentary; resulting investigations found flaws in the uniformity of the cells (basically, he only edited some of them) and the fact that the girls had very little chance of contracting HIV made many question the experiment’s purpose. But the scientific attention to this case wasn’t really about HIV, or the girls, or the experiment. It was about the implications of an emerging gene-edited world.

To many people, these children - called “designer babies” - were omens of a better tomorrow. Mr. He claimed that after his work was publicized, he received dozens of letters from parents of children with cystic fibrosis and other genetic disorders, asking him to help their children. In He’s mind, and the minds of his supporters, gene-editing could lead to a higher quality of life for millions of people worldwide, who would otherwise suffer from certain genetic disorders. For them this research could very well be the beginning of more effective treatment or even cures for some of the most brutal ailments that plague humanity. To take two examples, Tay-Sachs disease, which typically kills children before they reach school age, and hemophilia, a blood-clotting disorder that makes minor injuries potentially deadly, could be helped by further development of this technology.

Technology, however, has never existed in a vacuum. It always reflects the priorities of its creators and their societies. Many predict that gene-editing will only exacerbate existing social inequalities, such as class hierarchies. Those with the resources to control these technologies could create a group of humans that are “better” in the sense of smarter, physically stronger, and more resistant to some diseases than their counterparts. Imagine, in fifty years, some say, a child with disabilities who has no accommodations available to her because disabilities have become a thing of the past – and thus not a priority – for the more powerful members of society. Or imagine racial and ethnic prejudices leading to those with a certain skin tone, eye color, or bone structure being simply edited into uniformity; imagine how much worse life would get for the unedited poorer classes who would become an even smaller and weaker minority.

Discussion Questions

1. Can we distinguish ethically permissible from ethically impermissible use of gene-editing?
2. Who decides which traits are “normal,” and which constitute a disability or disorder?
3. Will the high costs of gene-editing make it available only to the wealthy?