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Also in this issue: "The Need for a Catholic Neuroethics," by James Beauregard

## THE ETHICAL CHALLENGES OF GENE EDITING

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In August 2017, researchers at the Oregon Health and Science University announced that they had successfully used a gene editing technique known as CRISPR-Cas9 to repair disease-causing genes in human embryos.<sup>1</sup> Some members of the scientific and medical communities have hailed the development as a way to ensure that life-threatening diseases are not passed on to future generations. But is gene editing always a good thing?

The Catholic Church encourages scientific research that is ethical and serves the human good. In the future, CRISPR may be used to treat people with serious genetic diseases, such as hemophilia and sickle-cell anemia. However, for research on human beings to be ethical, it must be strictly therapeutic and must respect the dignity and sacredness of human life.<sup>2</sup> Gene-editing techniques raise profound ethical challenges in both respects.<sup>3</sup>

### Ethical Concerns with Gene-Editing Research Using Human Embryos

1. Researchers using human embryos for genetic experiments are in effect treating them as objects, means to the researchers' investigative ends, not as ends in themselves.
2. Genetic research is generally carried out on human embryos created through IVF, an intrinsically immoral means of bringing new human life into the world.
3. Genetic experiments are conducted on the embryos without their consent. Furthermore, the individuals who produce these embryos or contribute gametes to their production do not have the authority to give consent to their destruction.
4. Genetically modified embryos are deliberately destroyed after the research protocol is completed, manifesting a kill-to-cure mentality that exists among some members of the scientific community.

5. Such exploitation denigrates the intrinsic value of the embryo, denying him or her the dignity and respect proper to human persons.

### Ethical Concerns with Future Applications of Gene Editing

1. No one knows the long-term consequences of human gene editing, especially when it is carried out during the early phases of human development. The process could introduce complications that we are not aware of and cannot anticipate. For this reason, all such research must first be extensively and carefully studied in animals before any human therapies are attempted.
2. Gene editing of embryos can affect the germ line, thereby introducing permanent alterations not only to the person who receives treatment but to his or her descendants as well.
3. How do we define "defect" and determine which ones to target with gene editing? Is baldness a defect? What about height or weight?
4. There has been little discussion on how the availability of gene editing will affect people with genetic disabilities. Will these individuals be pressured to undergo therapy to "cure" their condition? What will happen to people who choose not to undergo treatment, particularly when it comes to accessing medical care and social services? Similarly, will the parents of unborn children who are diagnosed with genetic disabilities be compelled implicitly or explicitly to pursue treatment? How will society view parents who decline treatment? Will their choice invite prejudice and discrimination against them and their children?
5. If gene editing is perfected, it will be used not only for therapeutic purposes but also for enhancement, that is, to engender or modify human beings with "desirable" genetic characteristics. This is clearly a move down the road to eugenics—the effort to improve the human species by eliminating "undesirable" traits and seeking out "desirable" ones. The questions to ask concerning eugenics are similar to the ones asked above: Which genetic traits are desirable, and which are undesirable? Who will make these determinations, and who will adjudicate the

many competing claims that will inevitably arise from them?

If gene editing is used for enhancement, it will undermine the parent–child relationship by offering parents the ability to control their children’s biology by choosing the genetic traits that they want their children to have or not have. This power reinforces the cultural norms of individualistic autonomy and perfectionism, with children being engendered as objects to meet the needs of their parents, not as human persons of value in themselves. This raises the question of whether children will be loved for who they are or for who their parents want them to be.

Medical research is an essential part of understanding and treating diseases, including genetic disorders. We should applaud the efforts of those in the medical sciences who study the human genome with the goal of improving

human health. Yet medical research is not value-free. It must always be conducted within the bounds of reason and objective moral truth. Today this cannot be said for some uses of gene editing. Because this technology is being used to exploit nascent human life and still faces profound, unanswered ethical questions, gene editing needs additional oversight and guidance within a broader and more critical ethical framework.

#### Notes

1. Heidi Ledford, “CRISPR Fixes Disease Gene in Viable Human Embryos,” *Nature* 548.7665 (October 3, 2017): 13–14, doi:10.1038/nature.2017.22382.
2. US Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (Washington DC: USCCB, 2009), dir. 31, 33, 51.
3. Several of these concerns are adapted from media interviews given by ethicists at The National Catholic Bioethics Center in the days following the August 2017 announcement on gene editing.