



BIOETHICS FORUM ESSAY

The Nebulous Ethics of Human Germline Gene Editing

<http://www.thehastingscenter.org/nebulous-ethics-human-germline-gene-editing/>

By Josephine Johnston

Should scientists pursue research that would enable prospective parents to edit the genes of their future children in ways that could be passed onto subsequent generations? Not for now, according to the organizers (<http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a>) of a summit held in Washington DC at the end of 2015. The three day International Summit on Human Gene Editing (<http://nationalacademies.org/gene-editing/Gene-Edit-Summit/>) was co-hosted by the US's National Academy of Sciences, and National Academy of Medicine, the UK's Royal Society, and the Chinese Academy of Sciences. Its goal was to consider a variety of possible uses of gene editing technology in humans.

At the end of the Summit, the Organizing Committee endorsed some potential uses of the technology—such as to treat cancer or confer immunity to infectious diseases—if those uses could meet existing standards for safety and effectiveness. But the Committee also raised a variety of unresolved issues about the use of technologies like CRISPR-Cas9 to alter the genes of eggs, sperm or early stage embryos. In addition to questions about safety and efficacy, they listed concerns about exacerbating social inequalities and about “the moral and ethical considerations in purposefully altering human evolution.”

(<http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a>) These concerns would persist even if researchers succeeded in developing safe, efficacious ways to alter human genes.

The idea that biomedical technologies should be tested to ensure that they work and don't cause harm is deeply familiar to most people and requires little justification in the public square. Concerns about the potential for new technologies to exacerbate inequalities, as well as the risk that they might be applied coercively, are also familiar. But the Committee's phrase "moral and ethical considerations" is more mysterious. What are these considerations, and what role should they play in science policy?

To some, the phrase "moral and ethical considerations" includes the idea that the human genome is inviolable, because it is a sacred gift or because it belongs to all of humanity, including future generations. To alter it is to 'Play God.' To others, the phrase includes the argument that altering the human germline is contrary to human dignity (http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html). These ideas—and others like them—have been dismissed (<http://www.bmj.com/content/327/7429/1419>) by some commentators as irrelevant to public debate because they are rooted in particular religions, or because they are too nebulous and sweeping to be useful (<https://www.bostonglobe.com/opinion/2015/07/31/the-moral-imperative-for-bioethics/JmEkoyzITAu9oQV76JrK9N/story.html>) in guiding science policy.

But what if there is something to them? What if 'Playing God' can refer not to usurping a deity but to taking on an extraordinary and unprecedented degree of control over the genetic makeup of oneself or one's future children? We are accustomed to thinking of control as an unmitigated good. But maybe the 'Playing God' concern is a way of noticing the downsides of control. Particularly in reproductive contexts, the introduction of technologies like IVF and prenatal testing (and perhaps soon gene editing) can generate new responsibilities. The promise of control can put new obligations on prospective parents to maximize the genetic 'fitness' of their future children, thereby altering the nature of parenting and—crucially—the *experience* of creating a family.

For many of us, parenting is about (<https://aeon.co/essays/can-parents-be-trusted-with-gene-editing-technology>) balancing the obligation to shape our children and to accept them for who they turn out to be. This balancing is a core part of what makes the parenting experience so wonderful (and so wonderfully difficult). Technologies like gene editing, which emphasize control, could disrupt or damage the parenting experience by tipping us towards 'making' and 'shaping' our children. The new parenting experience would involve fewer surprises. The new parent wouldn't need to practice as much acceptance of their child. What might it feel like to be this new kind of 'maker' parent?

This is just one example of a kind of moral reasoning that can help us discriminate between uses of gene editing technologies that will and will not make our lives better—that will and will not help us to *flourish*—over and above making us healthier or more productive. A discussion invoking flourishing—or living a good life—can be difficult in a diverse society. Yet, it is just the kind of conversation we need, and that I hope can happen under the broad heading of "ethical and moral considerations."

The current *de facto* international moratorium on human germline gene editing is a temporary halt. It is recommended until (<http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a>) “the relevant safety and efficacy issues have been resolved” and “there is broad societal consensus about the appropriateness of the proposed application.” As we work towards such a consensus, we should consider the full range of “moral and ethical considerations,” including ‘Playing God.’ I hope that we will give those concerns a creative hearing, asking what they mean for us today and how they can help us use this new and in many ways very promising technology to truly advance our flourishing.

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