Making Sense of Bioethics December, 2018 Father Tad Pacholczyk Director of Education The National Catholic Bioethics Center



Gene-Edited Babies and the Runaway Train of IVF

Should JK's human gene editing work be condemned and should he be branded as a rogue scientist violating significant moral boundaries? The answer will, in fact, be linked to whether we understand IVF to be ethical or not...



In November 2018, a Chinese scientist named He Jankui (known to his associates as "JK") claimed that he had successfully produced the world's first gene-edited human babies using "gene surgery." The twin girls, he said, were born somewhere in China with a modified gene that makes them immune to infection from HIV, the virus that causes AIDS. A special DNA splicing technique called CRISPR/ Cas 9 was used when they were embryos to make the edits. In a series of short videos posted on YouTube, JK offers an explanation of, and justification for, what he did.

He reminds his viewers that when scientists first began doing *in vitro* fertilization (IVF) in 1978, a number of ethical concerns were raised, but those mostly subsided over time:

> "The media hyped panic about Louise Brown's birth as the first IVF baby. But for forty years, regulations and morals have developed together with IVF, ensuring only therapeutic applications to help more than 8 million children come into this world. Gene surgery is another IVF advancement."

In another video, he puts it this way:

"Look back to the 1970s with Louise Brown. The same fears and criticisms then are repeated now. Yet, IVF unquestionably has benefited families. There will be no question about the morality of gene surgery in 20 to 30 years."

JK's strong conclusion leads us to ask whether the general sense of revulsion that has arisen towards his gene-editing work is merely alarmist and shortsighted. Are people failing to grasp the importance and propriety of what he is doing? Is he a pioneer ushering in a new age of enlightenment where mankind will be able to make use of the powers of science to achieve good ends? Or should his gene editing work be condemned and JK branded as a rogue scientist violating significant moral boundaries?

The answer to these questions will, in fact, be linked to whether we understand IVF to be ethical or not — JK is right to draw the parallel. If we conclude that IVF is something good and ethically acceptable, we end up granting the principle that it is OK to engage in very harmful and damaging actions as long as we have a good end or purpose in mind. Although IVF involves a

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litany of grave harms, like the engendering of human beings in laboratories and the freezing or destruction of embryos, if our intention is to help others fulfill their desire to have a baby, it must be OK. By this same logic, gene editing of our children will also be considered acceptable as long as our intentions are good and we're trying to help others, even if we're actually causing serious harms along the way.

Adding up the grave harms from IVF gives us a long list: IVF turns procreation into "production." It dehumanizes embryonic children, treating them as objects to be frozen, manipulated, abandoned or destroyed. Since the practice began in 1978, millions of embryos have become warehoused in liquid nitrogen, abandoned in frozen "orphanages." Millions more have been outright discarded as biomedical waste. Instead of "loving our children into being" through the one-flesh union of husband and wife, IVF mass-produces children in clinics, assemblyline style, under the impetus of market capitalism. Children born by IVF, moreover, experience roughly double the rate of birth defects of regularly conceived children.

Over the years, these kinds of

concerns have been mostly glossed over or ignored — we've grown accustomed to frozen orphanages, and to the high toll involved in the process of assuring that a few of our embryonic children survive and successfully implant. We downplay the risk of birth defects. Our insensitivity and desires have trumped a clear sense of ethics.

As we face the daunting question of editing human embryos, we run up against the same temptation. Editing our embryonic children to be free of a particular disease requires numerous embryos to be simultaneously created (or thawed out), treated as "products" and subjected to genetic "treatments," with many of them perishing during the experiment, in order that a few of them might survive and develop without the disease. Editing our embryonic children may also involve risks to them that we will only understand later when they grow up. Is it ever proper to experiment on our own offspring? Moreover, gene editing in embryos introduces changes that will be passed into the human gene pool, establishing permanent and irrevocable changes to our own humanity. How does one adequately evaluate the risks of such changes?

The fact remains that we've been willing to tolerate an abundance of human carnage up to this point with IVF, and one of the great tragedies of our age has been our tone deafness to the evils of IVF. JK argues that we are similarly poised to accept the production of gene-edited babies as yet another variation on the theme.

Will his brazen instrumentalization of human beings call forth gasps of disbelief, serious reflection and action, or only a few more passing yawns?

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