Israeli experts pan Chinese gene-editing as ‘drastic’ human experimentation

‘When you are about to make such a large change to humanity, shouldn’t you consult with the human race?’ asks bioethics chair

By Marissa Newman 29 November 2018, 6:42 pm 0

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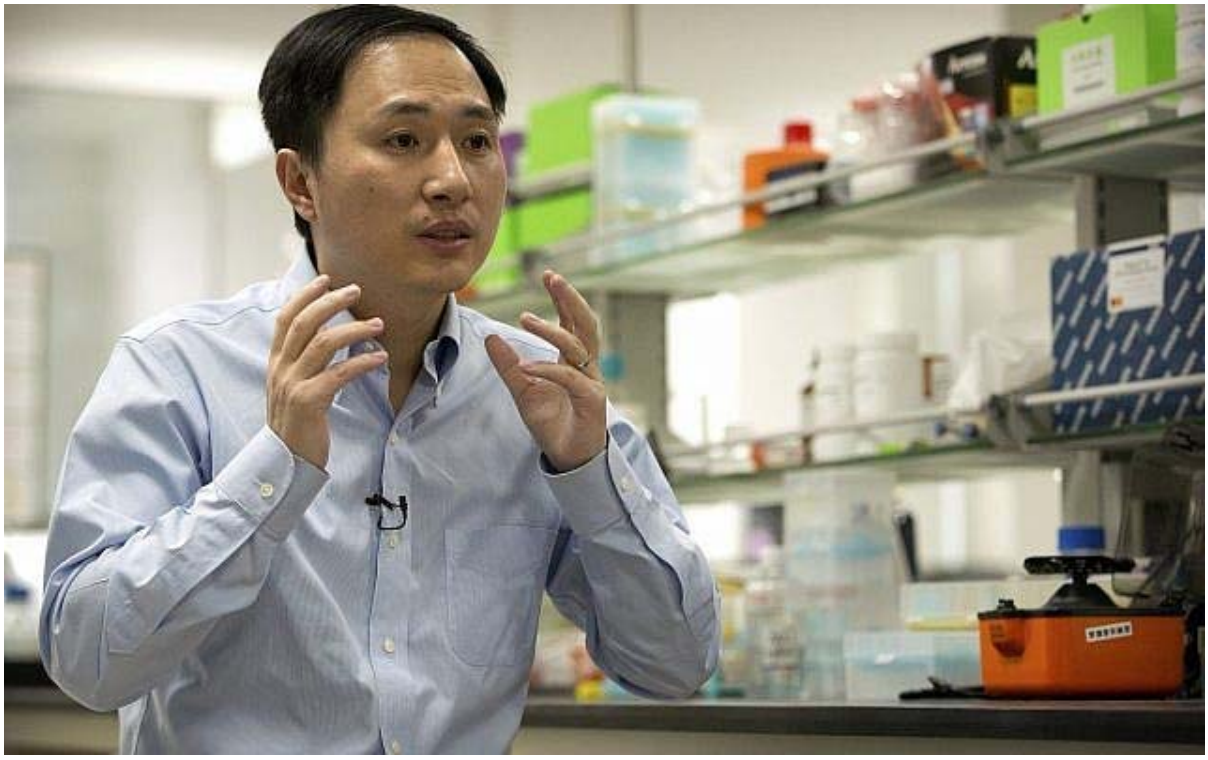

In this Oct. 10, 2018 photo, He Jiankui speaks during an interview at a laboratory in Shenzhen in southern China's Guangdong province. (AP/Mark Schiefelbein)

Israeli bioethics experts have joined an international chorus of shock and condemnation over a rogue Chinese scientist’s claim that he helped make the world’s first gene-edited babies, in a move one said was tantamount to changing the human race without its consent.

Researcher He Jiankui claims to have altered the DNA of a pair of twins to try to make them resistant to infection with the AIDS virus. Mainstream scientists — with the exception of Harvard University’s George Church — have condemned the

experiment, and universities and government groups are investigating. There is no independent confirmation of He's claims.

On Thursday China ordered a halt to He's scientific activities and warned he may have broken the law.

Dr. Otniel Dror, chair of the Bioethics Advisory Committee of the Israel Academy of Sciences and Humanities, listed a series of ethical missteps by He, arguing that "drastic" experimentation should not have been exercised when other medical options are readily available for preventing the transmission of HIV from HIV positive fathers to their offspring.

The treatment was unnecessary for the fully healthy babies and the edited genes will now be passed on to their progeny with numerous unforeseen repercussions, Dror told The Times of Israel. Though the parents allegedly signed off on the procedure, they may not have been aware of other medical options, and the twin girls whose genes were edited had no input in the decision that will affect their lives, he continued.

Moreover, Dror stressed, He jumped the gun without approval from international vetting committees or a proof of concept, and should have waited for global consensus on the clinical application of the procedure.

"What will be with the next generations? We don't know what effects it will have. He released this on the human race — it's not limited to a single human being — and now all the descendants of these children, they will be people who have undergone this editing," he said.

"When you are about to make such a large change to humanity, shouldn't you consult with the human race?" he said.

Eight volunteer couples — HIV-positive fathers and HIV-negative mothers — signed up to the trial, with one dropping out before it was put on hold. He said there had been "another potential pregnancy" involving a second couple, but it is unclear whether that pregnancy is still ongoing.

China's National Health Commission on Thursday said it had ordered an investigation into He's experiment. Chinese science and technology vice minister Xu Nanping said the "gene-edited babies incident as reported by media blatantly violated our country's relevant laws and regulations."

The claims were "shocking and unacceptable" and breached "the bottom line of morality and ethics that the academic community adheres to," he told CCTV.

The science and technology ministry "firmly opposes" the experiment and "has already demanded that the relevant organization suspend the scientific activities of relevant personnel," Xu added.

Dr. Shimon Glick, a bioethics expert and physician who helped found Ben-Gurion University's Faculty of Medicine, said there was global unanimity that "what he did was improper" and premature. While the claim has yet to be proven, Glick said that in theory, it was entirely possible that He had used the CRISPR-cas9 technology to make HIV-resistant babies, a procedure that would be illegal to carry out in Israel and the West.


Dr. Shimon Glick (YouTube screenshot)

In recent years scientists have discovered a relatively easy way to edit genes, the strands of DNA that govern the body. The tool, called CRISPR-cas9, makes it possible to operate on DNA to supply a needed gene or disable one that's causing problems. It's only recently been tried in adults to treat deadly diseases, and the changes are confined to that person. Editing sperm, eggs, or embryos is different — the changes can be inherited. In the US the process in not allowed except for lab research purposes. China outlaws human cloning but not specifically gene editing.

A group of leading scientists gathered in Hong Kong this week for an international conference on gene editing. The confab was rocked by He's revelation on Monday to one of the organizers of an international conference, and earlier in exclusive interviews with The Associated Press.

Although the science holds promise for helping those already born and studies testing such applications are underway, a statement issued Thursday by the 14-member conference leaders says it's irresponsible to try it on eggs, sperm, or embryos except in lab research, because not enough is known yet about its risks or safety.

"In the world, there is a consensus not to carry out genetic treatments that are passed on to future generations. This is a fact," added Prof. Yechiel Michael Barilan of the Sackler Faculty of Medicine at Tel Aviv University.

What does the future hold?

Despite the vocal opposition from the scientific community, He's jaw-dropping claim earlier this week unleashed a feverish global wave of speculation on the future of

gene-editing, from the prospects of curing diseases to the possibilities of human enhancement and production of so-called “designer babies.”

“It’s fairly obvious to me… that there will be a consensus that at first, we will do it for people who are sick,” Dror, a historian, doctor, and professor at the Hebrew University of Jerusalem, predicted of the future of genetic engineering. But from there, he said, the line between treatment and enhancement could easily become blurred, with even tweaks to code to cure diseases inadvertently resulting in various other forms of enhancement.

While he didn’t write off enhancement per se, Dror outlined numerous ethical dilemmas that genetic modification could theoretically pose, raising as an example those who would seek to change their skin color or racial characteristics to avoid discrimination, when the moral social response would be to stamp out the hatred. Parents could determine much of their children’s makeup, without the “interactions” and “negotiations” in parenting, whereby children are free to reject certain precepts of their upbringing, he said. And the gene-editing would likely deepen social inequalities, as it would only be accessible to those of financial means.


Human DNA strand (iStock by Getty Images)

For treatment, there is also the matter of “what society believes is an illness,” he said, which is not “based solely on biology.”

“The classic example in the West in the 20th century is homosexuality, which was treated as a disease, by doctors. And then society decided it wasn’t a disease,” he said, also mentioning former cultural perceptions of epilepsy, and anorexia nervosa among ascetic Christian women.

Glick and Barilan also did not rule out future gene enhancement once the science was honed and risks were fully understood, with both saying it was analogous to the medical development of plastic surgery.

There is “always a possibility medicine can be corrupted,” Glick acknowledged, likening it to the use and misuse of fire and guns. But in a 2011 paper, Glick, in a

“thought experiment,” favored enhancement, if the risks were resolved and the procedures were reversible.

“Enhancement has often been described pejoratively in terms of a parent who wants his child to be eight feet tall because he aspires to have a son who will be a star basketball player, or by a variety of other such examples whose results might well restrict the child’s life opportunities in order to direct him/her into the specific pathway chosen by the parents,” he wrote.

“But enhancement, if used thoughtfully, could much more likely be used, for example, to improve a child’s musical talent in a family that has little such ability, or to improve a child’s IQ from low normal to high normal, or to enhance physical coordination. All of these various enhancements would not just improve the quality of the child’s life but might even prolong life and prevent disease, and would broaden the child’s opportunities rather than narrow them.”

In the paper, which argues that Jewish tradition would not be at odds with germ line modification, Glick also argued the dark history of eugenics should not deter scientists from all genetic intervention.

“This virus, which in its most malignant and extreme form of course infected Nazi Germany but did not leave democratic Western countries such as the USA and Scandinavian countries unscathed, has left its scars, appropriately so. On the other hand, the trauma of this unfortunate era must not yield to a paralyzing neurosis whereby blanket prohibition of genetic modification becomes the norm,” he said.