Genome Editing for Human Benefit: Ethics, Engagement and Governance

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Pecha Kucha: Analysis of China´s CRISPR babies using the Emanuel Framework

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Background

Last year, Chinese researcher Jiankui He announced that he had altered the genome of human embryos to make them resistant to HIV infection by using CRISPR/CAS 9 technique, initiating a firestorm of criticism, since this modification will pass on to future generations. Two apparently healthy twin girls were born and there are other on-going pregnancies with gene-edited embryos.[1] I will discuss this case as a teaching tool, using the Emanuel framework to assess the ethical issues raised by Dr. He's experiment. These criteria were proposed as guidelines for determining whether clinical research is ethically permissible.[2]

Ethical analysis

1. Social or scientific value: Research in humans should evaluate interventions that could improve health and/or well-being of the participants or generate relevant new knowledge. In this experiment, Dr. He used healthy embryos that did not need any therapy, and there are many other ways of preventing HIV infection. Consequently, social value was not demonstrated.

2. Scientific validity: To obtain valid results, research must be conducted with high scientific standards. At present, it remains unknown if this criterion was met.

3. Fair subject selection: The only reason given by Dr. He for using these embryos was the possibility to attain immunity to HIV[1], since the fathers were infected with HIV. However, only HIV infected mothers can affect the offspring in utero. Thus, this seems and invalid selection criteria.

4. Favorable risk-benefit ratio: In this case, healthy embryos were manipulated in such a way that future, still unforeseen, consequences cannot be ruled out. Thus, this experiment was not medically justified considering the risk/benefit analysis.

5. Independent review: Dr. He's study was not submitted to ethical approval and was conducted without any type of supervision.[2]

6. Informed consent: There are several ethical concerns regarding the informed consent obtained by Dr. He, including an incomplete disclosure of the information, the request for a confidential agreement, the payment to participants and the labeling of his study as an "AIDS vaccine development project".[3]

7. Respect for potential and enrolled subjects: In Dr. He's experiment, the newborns names were made public, arrangements for appropriate follow-ups were lacking, and withdrawing from the study was practically impossible because of its long-term consequences. Therefore, this criterion was not met.

Conclusion

A critical analysis of Dr. He's experiment is a useful tool for students and research ethics committee members to put in practice Emanuel ethical framework. Hopefully, it may promote an in depth discussion about global standards for producing such 'CRISPR-edited' babies[4], particularly when there is no intention to correct a serious genetic disorder that causes disease or disability.

References

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