

## **Statement of Intent**

I am studying the particular case of He Jiankui and his modification of two human embryos and examining the methods he used to conduct his study. I want to analyze how He Jiankui may have been unethical in how he conducted his experiments and not focus on the whether or not genetic engineering itself is ethical. I hope to highlight a case study in which genetic engineering was used unethically in order to hopefully guide more ethical applications in future genetic engineering projects in humans.

**A Care Ethics Analysis of Genetic Modification on Human Embryos**

STS Research Paper  
Presented to the Faculty of the  
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University of Virginia

By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

Signed: \_\_\_\_\_

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## Introduction

In 2018 a Chinese biophysics researcher of the name He Jiankui made a claim that would shock researchers around the world. Jiankui announced to the world that he had created the world's first genetically modified babies, a completely unprecedented scientific development (Greely, 2019).

The announcement garnered major attention from press and scientists alike. Some praised He Jiankui's research as a major advancement of the field of genetic engineering while others heavily criticized his research fearing the social and political consequences of genetically modifying a human (Greely, 2019). Despite the major publicity of the research there has been comparatively little discussion on the ethics He Jiankui employed when performing his studies. It is an undeniable fact that genetic engineering is already used in biomedical circles and that soon it will be applied to humans to varying degrees. As such, it is important to examine the case of He Jiankui to better understand how to a new technology can be used in an extremely poor fashion.

I will examine the case of He Jiankui using the framework of care ethics to demonstrate that He Jiankui performed his studies in a severely unethical manner and showcased a severe lack of care in the usage of a nascent technology. Specifically, I will illustrate how Jiankui violated his duty of care not only to the scientific community by failing to incorporate competence and responsibly, but also to the subjects of his by showing a lack of attentiveness in neglecting the needs of his research subjects and responsiveness by abusing his position of power over them in order to further his ambitions.

## **Background**

He Jiankui was an associate professor in the Department of Biology at the Southern University of Science and Technology in Shenzhen, China. In November of 2018 Jiankui announced to the world that he had developed the first genetically modified humans, two girls which are known by the pseudonyms Lulu and Nana (Li et al., 2019). Jiankui claimed that he used the genetic engineering tool known as CRISPR/Cas9 in order to target a gene known as CCR5. CCR5 produces a protein which certain types of HIV use to enter cells (Li et al., 2019). By disabling the gene, He Jiankui hoped that he could confer immunity to HIV in Lulu and Nana. The two girls were successfully born but it is unknown if there have been any long term effects on their health as a result of the genetic modification (Li et al., 2019).

## **Literature Review**

Since He Jiankui's announcement of his research there have been a plethora of research examining the ethical pitfalls of his research. The majority of this research focuses on the political and social implications of his research on the world or the failures of the Chinese government and institutions from preventing his research to even occur. However, this research usually avoids examining the moral failings of He Jiankui's research and the lack of care he showcased in conducting it.

Jiang-Bao Nie in *He Jiankui's Genetic Misadventure: Why Him? Why China?* outlines the system in China used to facilitate scientific advancement. He describes their model of science as "authoritarian and nationalistic" and often lacking in transparency. He also discusses how nationalism played a role in driving He Jiankui's research. While Nie examined the flaws in the Chinese system of science that allowed for He Jiankui to conduct his research he stops short of making any ethical claims of Jiankui abusing these flaws in order to progress his research.

*In He Jiankui's Genetic Misadventure: Part 3 What Are the Major Ethical Issues?* Jiang-Bao Nie and Alexander T.M. Cheung examine various ethical and moral issues that arose from He Jiankui's research. The article does point out some major ethical failings of He Jiankui such as making larger claims than were supported by the actual data and also ignoring international and Chinese regulations on genetic modifications and scientific research. Nie and Alexander do not, however, focus on making any final claims on the morality of the research or examine any abuses of power he may have used to achieve his goals.

Nie and Alexander also examine how He Jiankui may have conducted the experiment not only for scientific advancement but also for worldwide fame. According to Nie and Alexander; Jiankui announced his research in an unprofessional manner on YouTube on the eve of the Second International Summit on Human Genome Editing as means to garner fame and "consolidate and expand his gene commodification". The use of the word "commodification" strongly implies He Jiankui's motivations for his research were not spurred on by altruistic intentions or scientific curiosity rather selfish desire. While this condemnation of Jiankui casts doubt on his character, it does little to shed light on how his lack of character would result in the unethical production of results.

It is clear from these two papers that He Jiankui's research resulted from a combination of various factors with social and political sources. Both papers however do not make any ethical judgements on Jiankui's research practices or examine the abuses of power from his position as a senior researcher. For the purposes of this paper I will examine factors that allowed for Jiankui to successfully conduct his research using the framework of care ethics to determine the extent of Jiankui's unethical actions.

## **Conceptual Framework**

Care ethics exists as an ethical framework that places immense emphasis on relationships of care, interconnectivity, context and practicing empathy (Noddings, 2012). It does not place emphasis on general moral principles or rules or claim that the development of morals come about by learning general moral principles, it strongly considers context when a decision is being made on whether a behavior is ethical or not (van de Poel & Royakkers, n.d.). Care in this context is defined as “everything we do to maintain, continue and repair our world” so we can live in the best possible version of it as defined by Joan Tronto. Care ethics argues that we owe a duty of care to those we are connected to and harbor relations with whether they be coworkers, the environment or even family (van de Poel & Royakkers, n.d.).

There exist four key aspects of care ethics that can be used to further expand the ability of the framework to determine ethical behavior. These aspects are as follows: responsibility, competence, responsiveness and attentiveness (van de Poel & Royakkers, n.d.). Responsibility is defined as the obligation to respond and care for a need that exists due to a particular relationship. This sort of obligation is existent regardless of legal binding or already existing societal norms (Bartky, 1990). In order to be considered competent in accordance to care ethics one must not only acknowledge the need to care, but also must provide sufficient care so the need in question is met (van de Poel & Royakkers, n.d.). Attentiveness is the acknowledgement of the needs of others. In order to successfully implement any plan of care one must first actually acknowledge the existence of a need (van de Poel & Royakkers, n.d.). Responsiveness is possibly the most crucial aspect of care ethics as it places the greatest emphasis on power dynamics in a relationship. Responsiveness is the acknowledgement that in some relationships power is not shared equally and different parties in a relationship may have more or less power

than others. This can result in “weaker” parties being vulnerable to abuse. A responsive “stronger” party understands this and takes the necessary steps to avoid abuse.

Since genetic engineering has begun to develop significantly and application in people is inevitable there have been attempts to specifically apply care ethics to the field. The American Medical Association (AMA), one of the most influential medical research organizations in the world has developed a code of medical ethics for researchers who would be conducting genome editing on human beings. The key tenant is to implement “the same care and concern for the well-being of the research participants that they would for to whom they provide clinical care in a therapeutic relationship” (*Genome editing and the AMA Code of Medical Ethics*, n.d.). By taking into the consideration the nature of the relationship between the researcher(s) and the research subjects and declaring that it should represent a therapeutic relationship the AMA is using care ethics as a means to establish its code of conduct for genetic modification in humans.

In the following sections of this paper I will examine the case of He Jiankui’s genetic modification of human embryos and establish how the researcher acted unethically in conducting his research by using care ethics and the AMA’s care ethics-based *Code of Medical Ethics*. I will showcase how Jiankui had a relationship of care to the scientific community and his research subjects and failed to incorporate several of the major aspects of care ethics and therefore action unethically in his research. I will use the AMA’s *Code of Medical Ethics* in order to help further apply care ethics to the nascent field of genetic modification in humans.

## **Analysis**

He Jiankui severely failed in implementing the various protocols and guidelines set up by the AMA in order to incorporate care ethics into research involving genetic engineering in humans. In doing so He Jiankui illustrated an immense lack of the core virtues of the care ethics

framework: responsibility, competence, responsiveness and attentiveness. The research practices conducted by He Jiankui that resulted in the development of the first genetically human babies showcase a lack of these aspects of care ethics and its principles and thus Jiankui was unethical in his research.

### Responsibility

In regards to the case of He Jiankui one key relationship that exists is the one between the scientific community and Jiankui as a researcher. This relationship however was damaged by He Jiankui's actions. Within the context of care ethics responsibility exists as the major tenant for establishing a relationship between two parties as one party has an obligation to another party that must be upheld (Noddings, 2012). According to the AMA one key obligation any researcher of genetic modification in humans owes to the scientific community is to "Adhere to rigorous scientific and ethical standards in conducting, supervising and disseminating results of the research." (*Genome editing and the AMA Code of Medical Ethics*, n.d.). The portion of this protocol that is most important to the scientific community is adherence to rigorous scientific standards. As such the question becomes did, He Jiankui adhere to the strict scientific standards that he owed the scientific community?

For any experienced researcher it is important to show prior research similar to a researcher's current studies as they can act as a justification and also a proof of concept for further research in specific field. This becomes even more important when the research involves using human subjects for testing. He Jiankui did not list any of his prior research in any of his publications (Krimsky, 2019). There are no prior references to him having any experience modifying embryos of other species such as mice or primates prior to conducting his human trials (Nie et al., 2019). This is problematic for a number of reasons. Firstly, it casts doubt on the



Jiankui's actual qualifications when dealing with genetic modification since there is no evidence that he can actually perform such a complex procedure. Secondly there is no proof of concept that could justify the experiment to the scientific community. Since he had not performed the procedure in non-humans subjects it is unknown if his target goal of curing HIV through genetically modified embryo implementation could even be achieved thus making the advancement to human subjects premature and reckless.

Furthermore, Jiankui showed a lack of scientific integrity he owed to the scientific community by omitting important information from his publications. One of these omissions are the doctors that helped with the procedure (Regalado, n.d.). The study would firstly have to recruit couples who are tested positive for HIV, doctors to test these couples, fertility doctors to treat the patients and also obstetricians to actually deliver the babies. All of these doctors who should have been included as authors (Regalado, n.d.) are not. By not including these other authors Jiankui demonstrates a lack of integrity and respect to scientific standards. Additionally, Jiankui did not include information about the possible risks his research could have on the twins or even the parents of the children (NormileDec. 30 et al., 2019). Genetic modification of humans is an incredibly young procedure and a potentially dangerous one. It is irresponsible to omit the possible risks of his research to the community which his research should advance. His study could very well inspire others in the scientific community to follow suit and conduct similar experiments but without the potential knowledge of the dangers the technology holds to the subjects.

The lack of scientific integrity that was demonstrated by He Jiankui when conducting his research has number of factors that could have caused it to occur. Some would argue that many of them stem from possible lack of oversight seen in the Chinese government's administration of

scientific research, and an differing set of ethics in Chinese research. It seems potentially unfair to claim that a research project is unethical when the ethical standards of different nations may not align with each other. Afterall, who is to say that western ethical standards are the optimal standards for advancing science? This argument however assumes that the ethical standards in the west and China actually differ significantly. In *He Jiankui's Genetic Misadventure Part 2: How Different Are Chinese and Western Bioethics?* Jing-Bao Nie and Neil Pickering demonstrate that this simply is not true. According to Nie and Pickering following the announcement of Jiankui's publications;122 Chinese scientists issued strong condemnations of Jiankui's research. Additionally, top Chinese officials have described his experiments as "extremely abominable" and necessitating punishment. Nie and Pickering go on to say "China doesn't have a China-specific ethical framework that supports such experimentation.". It is clear that Jiankui violated not only western standards of ethics but also Chinese standards since there exists no real distinction between the two in regards to genetic engineering research. This is demonstrated by the significant outrage in the Chinese scientific community which heavily mirrored the reaction in the west and China's own nation guidelines which Jiankui did not follow.

Regardless of the reason it is clear that He Jiankui demonstrated a strong lack of responsibility to the scientific community in which he was in a care relationship with by omitting important information of those involved and also the possible risks that exist from human genetic modification while also possibly lacking the qualifications to conduct such a complex and potentially dangerous project.

### Competence

There are some who claim that He Jiankui's research provided to the scientific community valuable data. When using care ethics to examine an ethical dilemma one must not only take into account the acknowledgement of need and responsibility in a care relationship but also the level of competence shown in the care given (Bartky, 1990). Competence looks at the action of addressing a need and how effective it is. In the case being examined I will consider the results of He Jiankui's study and examine if it demonstrates a successful addition to the scientific community to determine if he acted competently.

The expressed research goal of Jiankui's research was to prevent HIV transmission in newborns fertilized through in-vitro fertilization. In the case of Jiankui's study the father of the twins was HIV positive and as a result could possibly pass on the virus to the children when his sperm was used to fertilize the mother's eggs (Cyranski, 2019). In order to prevent this, Jiankui made use of a protein complex known as CRISPR/Cas9 which allows for specific genes to be targeted and removed (Cyranski & Ledford, 2018). Jiankui wanted to target a gene called *CCR5* which produces a protein of the same name on the surfaces of cells. HIV activates the *CCR5* protein in order to enter cells and begin replicating (Li et al., 2019). By disabling *CCR5* the hope was that HIV could no longer enter cells and essentially become harmless to the host. On the surface the plan is biologically sound and could possibly work but the results tell a different story. Analysis of the genetic sequence of one of the twins that was presented in the Jiankui's publication showed a genetic phenomenon known as "mosaicism" (Krimsky, 2019). Genetic mosaicism occurs when there exists genetic variation within cells of the same type. In this case some of the cells in the twin expressed the desired CRISPR/Cas9 removal of *CCR5* which illustrates some competency, however some of the cells did not (Regalado, n.d.). This is a significant problem as it means that the HIV virus could still infect the cells that still possess the

CCR5 protein and remains dangerous to the host. Jiankui does not address this potential fault in his study publications (Regalado, n.d.). Additionally, it should be noted that the removal of CCR5 has been significantly linked with increased susceptibility to other viruses such as West Nile Virus (Glass et al., 2006). This has been a long-established fact in biology that He Jiankui should have been aware of before conducting his study (Glass et al., 2006). He Jiankui shows a lack of competence by firstly failing to achieve his expressed research goal. While failure in science can be a positive force for advancement, failure in this case was dangerous as the very lives of the twins depended on the success of the study. Furthermore, by not considering a biological fact that could make his experiment a detriment to the twins before starting, Jiankui showcased severe incompetence in his own field by not considering facts that should have halted his research. In essence He Jiankui failed to develop immunity to HIV in the twins while also increasing their susceptibility to other viruses. The result is a weak study that only illustrates a dangerous procedure and does little to advance the field while also possibly damaging the reputation of the Chinese scientific community and the lives of the twins.

#### Attentiveness and Responsiveness

The case in question has He Jiankui as the care provider and the subjects of the study as those in need. In order to determine if Jiankui was attentive to his subjects we must assess the needs of the parents and if Jiankui successfully recognized it. In order for care to be provided in a care relationship, the need for care first must be acknowledged by one of the parties involved. The provider of the care must focus on the party in need and abstain from their own desires in order to successfully incorporate this aspect of care ethics (Noddings, 2012).

The parents sought out Jiankui in hopes that he could help them conceive children in a safe fashion to prevent HIV transmission (Krimsky, 2019). The parents' need in this case is the

implementation of the father's sperm in a way that prevents HIV from being transmitted to the children. There is no expressed need by the parents to actually genetically modify the embryos to be immune. Furthermore, there already exists methods to perform the need of the parents. The sperm of the father can be washed and the virus completely removed from it (Nie et al., 2019). Jiankui was aware of this method and even performed it in this case (Nie & Pickering, 2018) therefor making any genetic modification of the embryos completely unnecessary to solve their issue. He Jiankui demonstrates a complete lack of attentiveness here because instead of using a proven, safe method that would be sufficient to solve the issue he instead chose to implement a risky and unproven procedure. The reason for such a decision is not entirely clear but according to Nie a desire for fame and other materialistic reasons are reasonable motives especially considering the way in which he announced his study to the world through YouTube (Nie et al., 2019). This further demonstrates a lack of attentiveness because Jiankui did not place the needs of his subjects before his own desires.

A key question that has not been discussed yet in this paper is why would the parents consent to such a procedure if safer means exist? The answer to that question exists in the fourth care ethic element, responsiveness. Responsiveness takes into consideration the potential of abuses of power that can occur due to uneven power dynamics (Verhoek, 2014). In this case the party in power is He Jiankui and the power he holds over his subjects is his expertise in his field. The AMA makes sure to implement responsiveness into their guidelines for genetic engineering. One key way they do this is ensuring important information such as risks and the actual benefits about a study are shared with the subjects before experiments; this is known as informed consent (*Genome editing and the AMA Code of Medical Ethics*, n.d.). A review of the informed consent document given to the parents before the study showcased several examples of Jiankui not

adhering to AMA standards. Firstly he uses complex technical language that would be difficult for people not educated in the science to understand (Krimsky, 2019). Secondly he does not discuss possible risks of the procedure and lastly does not mention that safer alternatives exist (Cyranoski & Ledford, 2018). The use of complex technical jargon is important as it could have swayed the opinion of the parents in favor of the procedure. More importantly the omission of the risks and alternatives are more than likely intentional in order to stifle any fear in the parents and submit to the procedure Jiankui desired. In doing so He Jiankui illustrates an abuse of his power by using his expertise in the field to withhold valuable information from the parents to garner their trust and consent to his study.

## **Conclusion**

The use of care ethics can be used to determine the ethics of how He Jiankui conducted his research on genetically engineered human babies. The four elements of care: attentiveness, responsibility, competence and responsiveness were all clearly violated by the means in which He Jiankui conducted his study. This analysis does not make any final judgments on the mortality of using genetic engineering on humans in general but it does aim to deconstruct and examine a case in which the technology was used recklessly and hopefully guide more responsible usage of it in the future **while also providing insight into why and how genetic engineering can be used to violate rights**. As a highly anticipated medical development, genetic engineering in humans shows great promise to alleviate many of the worst ailments known to humanity but also carries great risks. As such, ethical standards of its use must be developed and adhered to in order to maximize its many benefits and minimize its possible dangers to our society

**Word Count: 3764**

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