ORIGINAL ARTICLE

Genetically Engineered Babies: An Ethical Debate

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As genetic research has become more and more commonplace, the potential for individually selecting specific genes for future offspring has been explored. The possibility of the common use of this technology gives rise to many benefits and doubts about topics ranging from the technology itself to the religious implications. The technology could potentially eradicate genetic disorders such as cystic fibrosis, but it could also cause high levels of mutations in the genome that might be irreversible. Allowing the use of this technology would also produce economical concerns and debates between quality of life and stigmatization of differences. Overall, the pros and cons of the technology need to be carefully weighed before genetically engineering human children becomes widespread.

Controversy aside, the technology is being heavily researched. Conceptually, in order to produce a genetically engineered human child, more commonly known as a designer baby, the DNA in the germ cells of the parents must be manipulated to produce a desired genetic makeup. The resulting child then will have the presence or absence of whichever gene was selected for or against in order to ensure certain characteristics of the child, such as gender or absence of a disease1. The desired gene can either be introduced into or removed from an embryo's genome in vitro and then gestated in the mother's womb1. The technology first proved to be successful in ANDi, a rhesus monkey with an inserted gene from a jellyfish that made him glow.[3] The technology used is called human genetic germline modification (HGGM), in which genes in human germ cells are removed or replaced6. If the procedure is successful, the offspring will then have specifically chosen characteristics that will be inherited by the subsequent generation. More commonly at present, pre-implantation genetic diagnosis (PGD) is used to screen embryos for a particular characteristic and the DNA is not manipulated. Rather, many embryos are tested for traits in vitro and then a specific embryo is chosen for implantation. [10] PGD requires many embryos in order to perform the screens, and HGGM could completely replace PGD as a more effective technology for genetic manipulation.

The first major benefit of modification of the embryonic genome is that certain genetic diseases could be made obsolete by eliminating the disease-carrying gene. [6] For example, cystic fibrosis is caused by an identified single gene, which could be removed and replaced with a healthy version of the gene, which would then be inherited by any offspring, eradicating the disease entirely6. The process may also be successful in selecting for gender to help avoid certain sex-linked diseases such as hemophilia4. However, the child will no longer be the direct genetic combination of its parents leading to potential legal and social difficulties, such as a child feeling as though he is not a member of his own family. Therefore, genetic modification may heritably eradicate some diseases, but may also lead to problems for the offspring.

In addition to the controversy associated with heritability, the idea of disease curability also gives rise to great benefits as well as some potential disadvantages. First of all, using germ-line technology over other technologies such as PGD allows for the curability of a disorder that would otherwise be expressed in any offspring. For example, select individuals who suffer from Huntington's disease have two irregular genes. Therefore, all offspring will receive at least one copy of the faulty gene, ensuring symptoms of the disorder. [11] HGGD could guarantee that any offspring only had healthy versions of the gene, and consequently would not have symptoms of Huntington's disease. Curing a disease could also greatly increase quality of life for offspring by allowing them to function regularly in society and to live full and productive lives. However, eliminating certain diseases could also have detrimental effects. For example, if an individual has one copy of the sickle cell anemia gene and one copy of the healthy gene making him heterozygous, he is protected against malaria. Eliminating the sickle cell gene completely would then actually raise morbidity levels resulting from malaria by eliminating the heterozygous population5. The greater implication is that a gene now thought to be only harmful could also be protective, and eliminating that gene could increase levels of other diseases. However, issues such as disease heritability and curability take a backseat to the issues with the technology, itself.

The most controversial issue has to do with the advantages and safety problems with the technology. Promotion of HGGM may make somatic cell technology completely replaceable with genetic changes being heritable rather than singly generational6. However, there are multiple safety concerns keeping the technology from being used in humans, at all. As the technology currently stands, it is extremely difficult to insert the gene into the genome at all, and if inserted, often the gene is not expressed. For example, when ANDi was being engineered, only three embryos of the 20 used actually glowed. [3] Lack of gene expression may occur because it is difficult to directly insert the gene where it is intended to go, and random insertion often occurs1. Since many different copies of the gene are required to even contemplate success, sometimes multiple copies of the gene are inserted where there should only be one copy, or the place in which the gene has been inserted interferes with expression of other genes necessary for the animal to survive, giving rise to over expression,

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under expression, or expression of genes in new places5. For example, when a new growth-hormone gene was added to pigs, the gene was successfully expressed and the pigs grew faster, but they also showed other unintended effects such as arthritis and gastric ulcers. [7]

There are other safety concerns, including high levels of mutagenicity found in manipulated chromosomes9. In addition, even if a gene is inserted in the correct place, most embryos die giving rise to spontaneous miscarriages or premature death. The two other fetuses that also glowed along with ANDi were both spontaneously aborted.[3] Finally, since all results will be heritable, all offspring will have the same problems as the parent generation, meaning without further technology, the process is virtually irreversible. Without fixing some of these problems, the technology cannot be used in humans.

If safety improves and HGGM assists in curing disease, the next step would be to allow parents to customize their own offspring. Parents would be able to select for a trait that would make the child more convenient to take care of in their family. For example two deaf parents who wanted to ensure they would have a deaf child to share in their language and cultural identity could select for a deaf gene8. However, some people believe that it is unfair to intentionally impair a child and deny them regular opportunities afforded other children8. In the bigger picture, some people liken choosing genes to eugenics and genetic "improvement," eliminating certain differences and traits and picking others.[1] Already, in certain cultures having a male child is much more valuable and steps are taken to reduce the likelihood that the child will be female4. Choosing specific traits for a child could stigmatize differences for those who were not genetically engineered and create a society intolerant of certain characteristics. There would be a fine line as to when this technology should be used and for what reasons.

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Some of the reasons for the use or nonuse of the technology would come from a religious standpoint. If a child is engineered to not have a disease before implantation, fewer individuals will have to make the ethically difficult decision to have an abortion6. HGGM also eliminates the necessity to use PGD and sacrifice multiple embryos to find one with a specific genetic makeup. However, for those who do believe in a god, they argue that the process of conception is a natural occurrence responsive only to divine intervention. Therefore, individuals who try to choose their child's traits are "playing God".[9] In addition, as the technology currently stands, genetic modification more likely than not will harm the fetus in some way, such as the aforementioned miscarriages of the rhesus monkeys.[3] Religious factions play a large role in decision making in the United States, and their concerns could not be ignored.

Another key determinant of when HGGM would be used has to do with money and cost. On one hand, it is much cheaper to remove a faulty gene than to care for a chronic or debilitating illness for years on end. However, as is true with most medical advances, the technology will only be available to wealthy people in wealthy countries for quite some time, indicating a global health injustice9. The concept is most certainly not a new one. For example, people living with HIV in low and middle-income countries such as South Africa, Cambodia, and Romania are much less likely to have access to antiretroviral medications (ARVs) because of cost than people living in countries like the United States. However, since 2001, many measures have been taken to lower drug prices leading to higher percentages of individuals able to take ARVs2. So, as with many medical technologies, with time and further research, the cost and accessibility of HGGM should increase. The technological and economical issues may be resolved in the near future, but some of the other ethical controversies may be much more difficult to solve.

The technology for customizing offspring via selecting for certain genes has been used successfully in animals. Although quite a few parts of the technology need to be made more reliable such as where the gene is inserted, the next step will be for its use in humans first to help eliminate certain disorders and then commercially to pick and choose particular desirable traits. The implications are vast and give rise to a multitude of questions about genetics, quality of life, religion, differences and cost. The day will come when final decisions need to be made about the ethics of engineering human offspring heritably and creating designer children.

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