

Ethical and Social Issues in Human Biotechnology

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Overview

As reproductive technologies have developed with the rapid spread of genetic engineering, embryology and cloning techniques, human biotechnology is now beginning to focus on the production of made-to-measure children with its quality control. In this chapter, some ethical and social issues are examined, which have been or will be mentioned in regard to techniques such as preimplantation, genetic diagnosis and embryo selection, donor baby, gene therapy of embryo, designer baby, cloned baby and artificial womb. A critical investigation is conducted on those competing opinions which justify such technologies on the basis of “reproductive freedom and rights” or “social benefit” on the one hand, and oppose them according to the principle of “human dignity” or “the welfare of the children” on the other. In conclusion, it is pointed out that we should regard these technologies as serious threats to the basic framework of human communication or interaction and thus monitor the development.

Introduction

The desire for infertile couples to have children using artificial means was the driving force in promoting the development of various reproductive technologies. This has covered a range up to a quality choice made about the child, not just in terms of “having the child” per se, but “what kind of child to have or to avoid having.” We will likely accelerate further in this direction with the growth of human biotechnology, which is promoted by the development of genetic engineering and embryology. Yet, reproductive technology, which is becoming a service responding to the needs of people as a market business, will move increasingly towards

choosing a “favorite product” from a catalog and, simultaneously, the disposal of “defective merchandise.” Thus, the children themselves, born by this very technology, will be cast aside, leading to the prevalence of evaluation standards of so-called pure quality “superior/inferior” children.

This article focuses on the techniques for manipulating human life in terms of reproduction and childbirth, and examines the ethical and social concerns of human biotechnology. Parties considering the use of these technologies under specific conditions will be predetermined, and we will attempt to show a number of typical views concerning the use of these technologies, and the methods of evaluating the pros and cons of selecting a child. We will present hypothetical examples of this not just as technologies already employed at present, but in terms of their potential uses in the near future. We will use each example and add to it some observations.

1. Preimplantation Genetic Diagnosis and Embryo Selection

[Scenario] A diagnosis of embryonic genetic traits is established, thus enabling the specification of genotypes for the onset of various kinds of diseases, making it possible to detect embryos which have a high risk of onset of those diseases. Mr. H, who suffers from a serious incurable and hereditary nerve disease, and his wife will choose an embryo which has no onset potential using a preimplantation genetic diagnosis from among multiple embryos created by in vitro fertilization, they have this embryo implanted into the wife’s womb, and are planning to have a healthy child.

[A] I, as a carrier of a certain fatal hereditary disease, lost my first child soon after it was born, while the 2nd child was prenatally diagnosed as having the strong likelihood of onset of the same disease I am carrying, thus the pregnancy was aborted. This agony could have been avoided if this type of embryo selection technology was available. In the first place, as the parents would be free to choose the type of child they will bring into this world, and would have the right to pursue happiness in the bearing and raising of a child which is healthy and normal, they should be allowed to make this choice.

[B] When considered according to what the parents should do for the best interests of the child, it would be a breach of duty and an abdication of responsibility as a parent not to do so despite there being a procedure to detect the risk of the onset of a disease. The government should provide subsidies for this technology to alleviate some of the costs of welfare services to patients with incurable diseases and persons with disabilities, so we are able to spread this technology.

[C] Screening out existence, where the mechanism of life starts, using a “normal or abnormal” yardstick, and getting rid of that which is “abnormal” amounts to the taking of innocent life, similar to abortion where the life of the fetus is ripped away from it. This is an act where equality in the value of life is lost, which can never be permitted.

[D] This procedure prevents persons with disabilities from being born, thus it may strengthen our value system, held by a considerable number of people that says “it’s better not to have persons with disabilities living in our world.” It would be impossible for persons with disabilities who continue to be looked at by their parents in a manner that suggests “if only this child was not here...” to accept this as the “freedom of choice of the parties concerned.”

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Preimplantation genetic diagnosis is currently performed principally for X-linked recessive disorders such as muscular dystrophy, single-gene disorders such as Huntington's disease and cystic fibrosis, and on a number of diseases where genotypes related to their onset are identified (such as Breast Cancer and Juvenile Alzheimer's Disease).

The question of whether to “permit unnecessary embryos to be discarded” is raised in the screening of embryos, where a line is drawn between “normal or abnormal” using certain standards. One of the arguments being made takes the view that if we eliminate the “abnormal” by doing so at the embryonic stage, there would be less ethical problems than at the fetal stage (selective abortion based on a prenatal diagnosis). There are, in any case, questions regarding the issue of the “moral status of the embryo.” Judged from the perspective that “life begins at

conception,” getting rid of an embryo is “killing” similar to taking life away from a fetus. On the contrary, there are no problems whatsoever when judged from the perspective that “since neither the embryos nor fetuses have individual persons as of yet, we can allow for them to be used in experiments or to be destroyed.” Among researchers, the prevailing view is that experimental use and disposal of embryos and fetuses can be allowed because they are not humans in any individual sense, up to 14 days after conception, where the primitive streak that is the spinal cord will, in good time, be formed.

However, is not the crux of the problem really in the ethical and societal implications of preferring to act to “prevent the birth of an abnormal embryo that will result, before long, in a disabled person?” Simply put, it is required to reply the question “does this pursuit not lead to discrimination against the disabled and eugenics?” The assertion that we should allow for this technology as a “right in the pursuit of happiness” assumes a value system which states that bearing and raising disabled persons and the burden of living with their disability is a “misfortune.” It is supported by a specific utilitarian concept that reduces welfare costs through preventing the birth of disabled persons. This kind of value judgment will certainly obliterate “equality in the value of life,” and may ignore the societal effect of promoting the view that the “disabled are expendable.” However, it is not easy to argue against the appeal that “this is the individual judgment of us, being the party concerned, so how can one state that this affects society?” There is also the powerful assertion being made that “preventing the birth of persons with disabilities may be compatible with strengthening welfare for the living disabled, so that the link between them is an inaccurate portrayal.” One may surely assume that “value judgments that state it is better that disabled persons not be born is not, in and of itself, discriminatory vis-à-vis the disabled.” Even so, it will be difficult to refute the claim “why do we not permit ourselves to use the means at our disposal to prevent the birth of a child, knowing that the child will suffer from an intractable disease?” The response to these questions may prescribe modalities in respective societies from their foundations.

2. Donor Baby

[Scenario] Mr. and Mrs. Y have a child diagnosed with severe leukemia, and are thinking of treating the sick child by having another child, in order to transplant hemopoietic stem cells from umbilical cord blood from this child to the child with leukemia. The plan calls for multiple embryos to be created using in vitro fertilization, the embryo with the strongest histocompatibility is selected based on gene diagnosis of all the embryos, then the mother is impregnated and later gives birth to a child.

[A] “Reproductive freedom and rights” entails not only deciding “whether to bear the child or not” and “when” but also the choice of “what kind of child is to be made.” When there is a clear objective in providing treatment to the child with leukemia as described in the above case, can we satisfactorily justify this procedure based on the rights of the parties concerned to pursue their happiness?

[B] In order to transplant bone marrow to the child with leukemia, we the parents would have a child by selecting an embryo using in vitro fertilization, which will lead to successful treatment, and both children are in good health. We shower our children with as much love as we have because they are irreplaceable, so we pray that Couple Y makes a good choice.

[C] Even when the purpose is to treat the child with leukemia, we cannot allow children to be created as a means to an end or as a tool. We lose our humility for “life, which is a blessing,” so we must place strict societal controls on this method of having a child, which shows contempt for life itself.

[D] The needed embryo, which meets a specific purpose, is being chosen, similar to the previous case, so naturally this is accompanied by disposing of the redundant embryos. We cannot accept that embryos, which have already begun vital activities as human beings and are totally normal, are to be disposed of based only on the selfish convenience of the couple who will bear the child.

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Preimplantation genetic diagnosis not only eliminates “abnormal embryos,” but

can be performed by selecting an embryo based on “desired characteristics.” Although only being able to choose gender or creating a donor baby as in Couple Y in the above plan are possible at present, there may be a breakthrough in the correlation between specific genotypes and human characteristics (athletic abilities, intellectual capabilities, artistic talents, criminal inclinations, etc.) in the future, and this may be put into use through embryo selection based on this achievement. The selection of embryos with specific qualities for some purposes means that we would be treating embryos like some sort of means to an end or as a tool. For example, in order for a couple who are both deaf or have achondroplasia to pass down their unique culture and lifestyle to their children, choosing to have a child with the same “impairment” as this couple through selecting the embryo have become the target of controversy.

Making embryos both the means and the tools is inseparable from making the existence of the child to be born from it a means and a tool. Are parents not being self-centered by creating a child with specific characteristics according to their own convenience? Obviously, one may be able to avoid criticisms by using the logic of “well, we will love our inimitable child, so we’re not treating it merely as a means to something, and at the same time, we respect its existence as an end in and of itself.” Yet, regardless of that, selecting a child for some purpose based on preset criteria (because it passed the ‘test’), there will still be the lingering problem of how these facts will prey upon the soul of a child born into this world. In other words, the question is “how will the reason for the child’s existence, being that it was born into this world because it possesses specific characteristics based on some sort of pretext, affect the child’s identity?”

One could also respond by stating that it is important for a parent with the obligation of raising that child to use every means at their disposal, and to convince and justify to that child why it was born into this world based on this means. However, the child may not accept that their origin was born based on the convenience of the parents, so strict societal controls will be required.

3. Gene Therapy of Embryo

[Scenario] Technologies are gradually being established to identify genes directly involved with the onset of some disease then eliminate these genes and replace them with normal ones. Embryos that can be manipulated through in vitro fertilization will be targeted for gene therapy using these technologies. Mr. and Mrs. K are a couple in which the wife carries a hereditary gene for Breast Cancer, and they would like to have a healthy child using gene therapy on embryos created through in vitro fertilization.

[A] This method, which prevents disease and disorders before they occur, is basically the same as normal therapies, and is not the concern of third parties other than the parties concerned. The desire of the parents to bear and raise a healthy child is the fundamental right to pursue happiness, and should, as a matter of course, be permitted.

[B] This treatment prevents the inheritance of factors of hereditary disease to successive generations, and is a watershed method in the eradication of those diseases, so it must become prevalent in order to improve the gene pool of the human race. When all carriers of genopathy factors have their own children, one can argue that they have a societal obligation to have this treatment performed.

[C] Tampering with genes of a germline will not just have still unconfirmed negative effects on the persons involved, but may also affect future generations. Even if the safety of this method was confirmed using animal experimentation, its clinical application will naturally be human experimentation, so great care should be taken in this stead.

[D] The growth of this technology will result not in the “blessing” of a child, but in a “product” which requires quality control, and may reinforce the natural trend to “fix the bad parts.” This would lead to the loss of human humility, and the fear is that we will tend to look down more and more on the value of life.

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When there is no possibility of creating a normal embryo without passing on affected genes, gene therapy of the germline is said to be appropriate. There are a

great number of guarded opinions internationally on this procedure at present. This is because there are concerns about “unknown future risks,” therefore, let’s try to focus in on these and evaluate them.

The benefits advocated by those arguing for its acceptance have stated that it contributes to advancements in medicine, the reproductive rights of carriers of hereditary diseases, it eliminates deleterious genes from the human gene pool, it cuts welfare budgets by reducing the number of disabled persons, and increases provisions to those who are currently disabled. In comparison to these concerns, there is little in terms of unknown and unproven biological risks in the future, and these will probably be eliminated through technological advancements. The wisdom of the human race to overcome hurdles became the driving force for our civilization. According to this concept, “bearing a baby as a product,” the “loss of humility,” and “violations to human dignity,” i.e. the argument to strengthen restrictions based on moral risks merely demonstrates a conservative attitude which turns its back on brilliant technological progress. Moreover, the ideology of neoliberalism, which entrusts the parties concerned with self determination and self responsibility vis-à-vis new technology developments and their uses, unless obvious risks to others or adverse effects to public order are revealed, supports the argument to work pro-actively to promote these rights. When these technologies spread, couples who choose to bear and raise a child with a hereditary disease without venturing to use these technologies will probably be exposed to discrimination and the stare of prejudice that will tell them “don’t count on public welfare support because its your responsibility.” They may also receive discriminatory treatment in education, employment, insurance coverage and other areas. We could expect that those who complain of these social risks will confronted by the response to the effect that sufficient measures will be taken via social policy, including legislation.

Assessing unknown future risks is related in some way to historical insight involving disabilities and discrimination, concern for our modern situation and the ability to imagine our future.

4. Designer Baby

[Scenario] The correlation between specific genotypes and phenotypes such as body functions & form is understood, leading to the establishment of technologies that manipulate embryos in order to achieve a certain aim. Mr. and Mrs. P are thinking of selecting a menu to improve their child's "memory" and "information processing skills" from a business service that offers this kind of "designer baby."

[A] It is natural for a parent, given the reality of the strong potential for the societal success of an individual who has superior talents, skills and intellect capabilities, to desire a child with these abilities. I believe that spending large sums for expenses to use this technology is contained within reproductive freedom and rights.

[B] The growth of our limitless desire to "go beyond the present" has driven the progress of our modern civilization, and we cannot hold it back. The human race, which has obtained both the knowledge and technology of genetic manipulation, will surely initiate steps towards a new evolution through self-transformation.

[C] The existence of these businesses, which meddle with life, demonstrate our appalling moral bankruptcy. We must never allow such behavior that commercializes children as tools of our own desires.

[D] This business, which is expected to incur tremendous costs, may prod some of the rich into a "gene-privileged class," and increase social inequalities. We should not invest limited social resources on this kind of technology research and development.

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This will lead to the establishment of technologies from eliminative interventions, whereby normal embryos will be discarded, to corrective interventions to turn abnormal embryos into normal ones, and enhance interventions, where normal embryos are turned into super embryos, and ultimately arrive at a point of the manipulation of life which will begin at in vitro fertilization. This is because the objective of having a child with desired characteristics will be achieved. Naturally, some physical and intellectual characteristics will not be determined simply through specific genotypes, so there will always be factors of

uncertainty, the consequences of which are not necessarily intended by the person doing the manipulations. Yet, contained in this is our adherence to the principles of self determination and self responsibility of the parties involved, thus the paradox in actively accepting the designing of children as a reproductive freedom and right is often called “new eugenics.”

Old eugenics strives to “improve our genetic quality” as an aggregate national policy, and it sometimes ignores the intent of the person by implementing measures such as marriage restrictions, contraception, abortions, sterilization treatments and curbs on immigration, and encouraging the making of “super” children. There are definitely sharp differences in this regard in terms of a new type of eugenics performed with the voluntary choice of the individual concerned. Nevertheless, both are common in that their aim is to intervene in the characteristics of human life based on a “superior/inferior” value measure. Eugenics needs to be perceived as an ideal and real-world campaign that continues its self transformation by incorporating the consequences of these technologies.

There are two main trends in new eugenics. The first one is “consumer eugenics” where the consumer purchases various services centered on the “choice of characteristics” offered by reproductive businesses, and the other is the “future eugenics oriented remodelling of human beings” which works to actively assess the promoting of the “self-transformation” or “self-evolution” of the human race while at the same time intervening in the genetic makeup of each individual. Both complement each other, and are expected to become driving forces for biotechnology.

5. Cloned Baby

[Scenario] Advances in the development of the somatic cell nuclear transfer cloning technique lead to its being introduced for fertility treatments, and later it is legalized as a cloned baby business which includes providing unfertilized eggs and host surrogacy in some countries. Ms. R, who lost her boyfriend in an accident, makes a request for a cloned baby which uses the somatic cells of her dead

boyfriend, and would like to raise the child created from those cells as a single mother.

[A] If my young child died in a medical mishap, I may wish to create a clone of my child. While I understand that the cloned child will not be an exact copy of my dead child, I would do it because I can heal the wound I have from losing the child I loved.

[B] If the person him/herself or the family of the deceased do not decline, cloning of elite scientists and politicians should proceed in earnest. This will surely have benefits in terms of the well-being of the human race in the future.

[C] Reproduction depends on the involvement of both the man and woman, thus human cloning that ignores this fact is an action where we lose genetic diversity and goes against nature, so it should be legally and completely prohibited. Intentionally creating life which has identical DNA is an infringement on human dignity as different and independent beings, and can never be accepted.

[D] Is it OK to create a child as if ordering a “product,” based on one’s desire and convenience? This is the instrumentalization of women done in the name of business, and the children to be born will be subject to prejudices and come under the scrutiny of the curious among us, so we should be cautious.

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The somatic cell nuclear transfer cloning technique is a procedure that was used to clone Dolly the sheep, and its application is applied to humans, and is called “reproductive cloning.” This is a technique in which the nuclei, which contains DNA information, is extracted from some somatic cells, then transplanted to unfertilized eggs which have their nuclei removed, after that the new nuclei are fused with the egg using electrical stimulation, cleavage starts, then those eggs which develop into embryos are implanted into the uterus. Examples of why this procedure is used are (1) where one of the persons in the couple is a carrier of a severe dominant genetic disease, (2) an infertile couple who does not desire fertility treatment using a third party, (3) for same sex couples, or single men and women, (4) as a substitute for a child who has died in an accident or as the result of illness

(5) as a donor for their own organ transplants, (6) as one's "double" to become the successor for the family or a business, (7) to copy "elites" in the arts and sports, and (8) to resurrect famous persons such as the founder of a religion or a politician.

Supporting the argument to accept this is, after all, reproductive freedom and rights. According to this argument, human cloning is not like creating a monster, as the child to be born will be not be any different from a normal child, thus this choice can be afforded to the persons concerned. The following probes the view that we should accept human cloning as a fertility treatment.

If we could refer to "a couple that wants a child but, for some reason, cannot have children is aided by technology to have a child" is a fertility treatment, then procedures to have a child which is genetically related to one or both persons are included in this. However, as those who implement the embryo selection through preimplantation diagnosis or germline genetic manipulation are not necessarily infertile, and its main aim is "selecting the child's characteristics" rather than "having a child," this cannot be considered a fertility treatment. Though human cloning seeks that the genetic relationship, the "desire for characteristics" for children who carry DNA which is identical to an individual already existing, wins out over the parents' and child's "desire for a relationship" manifested in normal medical technology for reproductive treatment.

It is, without a doubt, difficult to draw a clear line in the sand between both. However, when considered based on the identity of the child to be born, it appears that this difference is decisive. In other words, this is a difference between the self whose life exists in this world as a partner in the parent-child relationship, and the self whose being exists due to the aim of copying an individual who preceded them. Even if the DNA is identical, there will be great variations caused by environmental factors, thus even though the original and the clone have separate personalities, this difference must not be ignored. Therefore, human cloning will not be accepted as a "right to have children." Rather, we should state that it is "the right to choose a product equipped with specific characteristics," which cannot be justified.

6. Artificial Womb

[Scenario] As embryo created through in vitro fertilization is implanted into an artificial womb outside of the body, technology has been developed to carry out the pregnancy and childbirth, and artificial reproduction business providing this technology as a service are launched. Ms. F, a career woman, had an in vitro fertilized egg created with her boyfriend to avoid stopping her work due to pregnancy and childbirth, and she used this service to plan for her child.

[A] The woman believes there are great advantages for her to be free from the burden of pregnancy and childbirth. This technology may be adopted by a woman who has undergone a hysterectomy or cannot endure a pregnancy and doesn't want to put a halt to her working career or destroy her body line. So this provides her greater freedom of choice.

[B] If the practical application of artificial wombs realizes wide-ranging businesses that handle reproduction and childbirth for everything from providing sperm and eggs to human cloning, infertile couples as well as same sex couples and single men or women will be afforded the chance to have a child as they wish, when they like. This business is both suitable and superb for a variety of lifestyles.

[C] A bond is made between mother and child through the action of pregnancy and childbirth, so I do not intend to use it even if this technology is made available. The technology carries out the sacred role the woman has in pregnancy and childbirth, thus the worry is that the image of the woman as "a mere child-bearing machine" will be reinforced.

[D] This is the ultimate unnatural act, and we should be prohibited from studying it immediately. Being that a child is "one's own" is the foundation of the love between the mother and child, there is considerable unease about the effect that a "child born from a machine" will have on the psychological aspects of the child. With the trend being that children will be treated as "products" in a literal sense, it may erode our sense of awe about life.

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Two purported concepts are the development made by the Juntendo University

Group in Japan (1987) which led to a successful artificial womb (plastic tank) for incubating the fetus of a goat in a few weeks, and the development made by Cornell University, Weill Medical School Group in the US (2002) which led to combining this artificial womb with an artificial womb intima formed from uterine tissue, required for the implantation and development of an embryo. Yet, unraveling delicate in vivo mechanisms such as the endocrine system is extremely difficult, and is expected to take many years until they are put into practice. Though these techniques are anticipated for use in treatments where sustaining a pregnancy is dangerous to the life of the mother or the fetus must be removed from the womb due to it being a very low birth weight infant, its impact when realized is immeasurable.

Let's consider the question "are reproductive technologies, including artificial wombs, the gospel for the human race or are they something that will usher in the arrival of our worst nightmare?" The benefits from the "gospel" side of the argument are that women will be freed from the physical burden of pregnancy and childbirth, which will increase their freedom of choice, and contribute to various lifestyles thanks to multiple methods to have a child, among other benefits. This technology, which eliminates the voids in the career of women resulting from pregnancy and childbirth, the leading causes of societal disadvantages of women, is advocated as having revolutionary implications in realizing substantial gender equality. On the contrary, the side which says that this will bring about the "arrival of our worst nightmare" emphasizes the importance of the biological bond between mother and child, and the evils brought by the spread of this technology. Worries will be expressed about whether human beings themselves will be transformed into technological objects as we will be robbing ourselves of our primary communication, which forms the basis of human relations. Even so, the crux of the problems lies ahead. Let's try and recast these observations into a conclusion.

Conclusion

In vitro fertilization, embryo selection, and the development of an artificial womb

enable observations and manipulations to be performed outside of the mother's body at every stage from the creation of life to its birth, while control of the characteristics of life are reaching a level of completion. Interventions that eliminate or correct "undesirable" characteristics, and the selecting or reinforcing of "desirable" characteristics are quality control features that advance a full "production" process. Although this technology was already depicted as an "incubator" in the futuristic novel "Brave New World" (1932) by A. Huxley, this is a symbol of an anti-utopia used by the government as a tool for full reproductive control. Of course, if this is not a policy from above but a voluntary choice made by individuals, it will probably not lead immediately to a kind of techno-fascism. However, the effects on our value system, based on the viewpoint that advances in technologies which manipulate life will lead to a new understanding of others, particularly in the promotion of life as a "product" or "making life the object of manipulation or control," must not be ignored. The standardization of human beings under the name of individual freedom may be promoted, and a mentality which actively accepts control/or being controlled may be strengthened further.

How should we relate to the transformation of making children from "reproduction" to "product-making" or "manufacturing?" On the one hand, this is regarded as a new, evolutionary step for the human race created by the merging of life sciences and technology, so this process should be promoted further. On the other, there are many who present the negative view that this technology in and of itself merely violates humanity, robbing people of their humility, and reinforces our hubris. What we can say, perhaps, is that development of this technology may change how we create interpersonal relationships with each other from their very foundation, thus discretion and prudence are required.

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