Outlining boundaries: reflection on the ethical limits for applying genetic technologies

Denis Barbosa Cacique 1

Abstract

Outlining boundaries: reflection on the ethical limits for applying genetic technologies

This paper aims to develop a reflection on the ethical limits on genetic engineering uses in humans. For this, we sought to define ethical boundaries between the two purposes for genetic intervention, treatment and improvement. In addition, it was developed a brief historical retrospect of the eugenics' movements in Brazil, Germany, and the United States. We also have introduced some arguments often used against genetic interventions: the unnaturalness, the playing God, social cheating, the use of genetic information, the implications of germ cells manipulation and the logical resource to slippery slopes. The article ends with a warning on the need to establish public debate on the subject in order to facilitate the creation of ethical codes and legislation regulating the scientific and medical practices on the genetic manipulation technologies. This, however, requires necessarily a better quality of education and information of the Brazilian society, mainly in schools.

Key words: Genetics. Behavioral genetics. Genetic engineering. Genetic predisposition to disease. Genetic privacy. Eugenics.

Resumo

Este artigo objetiva desenvolver uma reflexão sobre os limites éticos para os usos da engenharia genética em humanos. Para tanto, buscou-se delinear fronteiras éticas entre as duas finalidades para intervenções genéticas: tratamento e melhoramento. Adicionalmente, foi desenvolvido breve retrospecto histórico sobre as investidas eugenistas eclodidas no Brasil, Alemanha e Estados Unidos. Também foram introduzidos argumentos frequentemente empregados contra as intervenções genéticas: a antinaturalidade, o brincar de Deus, a trapaça social, o uso de informações genéticas, as implicações da manipulação de células germinativas e o recurso lógico as ladeiras escorregadias. O artigo finaliza advertindo para a necessidade do estabelecimento de um debate publico sobre o tema, visando propiciar a criação de leis e códigos éticos reguladores da prática científica e médica sobre as tecnologias de manipulação genética. Contudo, tal fato demanda, necessariamente, melhor qualidade de educação e informação da sociedade brasileira, principalmente no âmbito escolar.

Palavras-chave: Genética. Genética comportamental. Engenharia genética. Predisposição genética para doença. Privacidade genética. Eugenia.

Resumen

Delimitación de las fronteras: reflexión sobre los límites éticos a la aplicación de las tecnologías genéticas

El objetivo de este trabajo es desarrollar una reflexión sobre los límites éticos a los usos de la ingeniería genética en los seres humanos. Para ello, hemos tratado de delinear los límites éticos entre los dos propósitos de la intervención genética: tratamiento y mejora. Además, se desarrollo una breve retrospectiva histórica de los movimientos de la eugenesia que tuvieron lugar en Brasil, Alemania y Estados Unidos. También se introdujeron los argumentos que se utilizan frecuentemente contra las intervenciones genéticas: la antinaturalidad, el jugar a ser Dios, la estafa social, el uso de las informaciones genéticas, las consecuencias de la manipulación de células germinales y el recurso lógico de pendientes resbaladizas. El artículo termina advirtiendo acerca de la necesidad del establecimiento de un debate público sobre el tema con el in de facilitar la creación de códigos de ética y leyes que regulan la práctica de la ciencia y la investigación médica en las tecnologías de manipulación genética. Esto, sin embargo, requiere necesariamente una mejor calidad de educación e información de la sociedad brasileña, especialmente en el ámbito escolar.

Palabras-clave: Genética. Genética comportamental. Ingeniería genética. Predisposición genética a la enfermedad. Privacidad genética. Eugenesia.

Contact address

Universidade Estadual de Campinas, Faculdade de Ciências Médicas, Departamento de Tocoginecologia. Alexander Fleming, Barào Geraldo, CEP 13081-970. Campinas/SP, Brasil.

He declares that there is not any conflict of interest.

^{1.} Master's degree student denisbarbosa.c@gmail.com - State University of Campinas (Unicamp), Campinas/SP, Brazil.

Once, the philosopher Hans Jonas drew attention to the dilemma of modern technique, which consists of the difficulty in determining beneficial and harmful technologies ¹. Genetic engineering is not the exception to this rule. On one hand, there are great expectations as to its possible benefits; on the other hand, a lot of trepidation. According to Schramm, possibilities of prevention and intervention in live organisms opened by genetic engineering awaken, at the same time, sentiments of fascination and astonishment ². For example, some authors warn of the existence of, in current times, eugenic practices camouflaged by the promise of a cure or with the aim of resolving the organic problems of the species - but often satisfying economic and political interests 3.

Based on the dilemma posed by Hans Jonas as to the difficulty of determining beneficial and harmful technologies, this article aims generate a reflection on the ethical limits for the uses of genetic engineering on human beings.

It deals, in truth, with a fairly recent scientific branch: even the treatment of genetic diseases is in its infancy, despite the fantasies and simplifications resurfacing in the media and popular imaginary ⁴. It is also true that humanity has been performing genetic manipulations for quite some ⁵. Many natural remedies are born from a patient process of observation, experimentation, and the selection of the best and most suitable ingredients and elements for certain ends, and this existed long before the flourishing of rigorous scientific methods. In agriculture, for example, the most adapted plants were selected and bred, the ones that bore the most fruit, the most resistant, and so on.

Genetic manipulation, therefore, is an old practice. The father of genetics himself, Gregor Mendel, made his important contributions still in the XIX century. However, it was after the 1970s, with the development of the first genetic engineering technique – recombinant DNA, by Paul Berg and his collaborators - that the production of scientific knowledge in this field sped up considerably. Since then, major steps were given. For example, the completion of the human genetic map, in 1995, by researchers of the Genome Project, as well as its almost complete sequencing eight years later.

Another conquest is the development of the first synthetic cell, recently announced by Gibson and collaborators⁶.

Therefore, although still in its infancy, genetic engineering already presents a history of significant conquests and it opens a world of possibilities - like the treatment of diseases and the improvement of several vegetable and animal species, including humans.

Genetic therapy

Analyzing the finalities, one basically identifies two types of genetic interventions in human beings: the therapeutic (also called, in time, negative eugenics) and improvement (or enhancement, or even positive eugenics). The application of genetic manipulation for therapeutic purposes constitutes the more acceptable form, from a moral perspective, for the use of this technology. To illustrate a possible application of genetic treatment, we use the case cystic fibrosis, the chronic disease that is common among Caucasians⁷, affecting one in every 2,500 people in Europe and with a similar incidence rate in the Brazilian Caucasian population⁸.

Cystic fibrosis is a genetically based illness, of an autosomal recessive origin and, until now, incurable ⁹. There are various ways of fighting it, which - it should be pointed out - still does not imply a cure. For example, medication may alleviate most symptoms, controlling digestive problems and reducing the risks of pulmonary infection. In face of the difficulty of definitively treating the problem, an alternative is to avoid the birth of people carrying this condition through the interruption of the pregnancy - this practice, however, is prohibited by law in Brazil ¹⁰.

To this end, pre-natal genetic exams are performed on fetuses whose parents have had children with this disease. The techniques for this type of diagnostic have been available since 1985^{11,12}, enabling parents to choose whether they wish to take the pregnancy to term or not. But the most expected response to this disease is the development is somatic cell gene therapy to not only treat the symptoms of the disease, but in fact its genetic cause ¹³.

In this case, we would be facing the so called *genetic treatment*, in other words, interventions aiming to combat health problems or deficiencies.

Genetic Enhancement

If, on one hand, genetic treatments enjoy ample support from secular and religious moral authorities ¹⁴, the same cannot be said for genetic improvement. The Houaiss dictionary defines *improvement* as a *change for the better; betterment and amelioration,* or *a movement forward; advances, progress, development* ¹⁵. In the case of genetics, this improvement intends not just to treat or prevent a disease, but another type of result, like, for example, increased height, intelligence, immunological resistance or some specific ability ¹⁶. Unlike genetic treatment, improvement aims for the perfecting of healthy systems or traits that are considered normal ¹⁴. It is, to all appearances, a positive thing.

However, the key issue surrounding this topic deals, precisely, with what one intends to improve¹⁷. Visual capacity? Height? Intelligence? Beauty? What? Why? And in whom? It is not possible to define a priori a generic solution for all these questions. To the contrary, it is necessary to evaluate each case, in a process that considers the perfected characteristics and their biopsychosocial implications. Either way, regardless of the answers that each case may achieve, Habermas criticism of so called liberal eugenics should be remembered, that does not recognize the boundary between therapeutic intervention and improvement, but leaves the choice of objectives relative to interventions that alter characteristics to the individual preferences of market participants ¹⁸.

Therefore, for the author, only interventions limited to a few and well defined cases of grave hereditary illnesses that could not be supported by the person potentially in question are morally admissible or lawfully justifiable. However, Habermas that such boundaries (moral and legal) will be overshadowed by the logic of the free market, that, endorsed by a liberal ideology, reduces the issue to the defense individual freedom for the seek out the improvements suitable to each person's preferences and resources.

Arguments and views against genetic intervention

One of the main criticisms on the idea of genetic improvement views the injustices that it may cause, in the sense that genetic improvement would constitute a kind of social trickery ¹⁴. Let us say, hypothetically, the case of a marathon runner whose resistance has been genetically improved. Their participation against normal athletes would tend to be unjust. Furthermore, the idea itself that someone may perfect their capacities in a lab seems to contradict the social value of natural improvement. For example, the improvement of the performance of an athlete through training is more valuable than that which is acquired through genetic interventions.

According to the World Anti-Doping Agency, the non-therapeutic use of cells, genes and gene elements or, even, the modulation of genetic expression, that have the capacity to increase athletic performance, is considered genetic *doping*, being, therefore, prohibited ¹⁹. New methods of detection of this novel style of *doping* are already being developed; however, according to specialists, the current technology still does not have a totally efficient means for this ^{20,21}. Such precautions arise from the knowledge that various genes would have the capacity of promoting substantial gains in athletic performance, which could be decisive in various sports ²², damaging, withal, the just competition between athletes.

And what should be said to someone who could achieve Nirvana without having to meditate, but simply for having their psychological capacity genetically improved? What would be the result of this improvement for the value of meditation? In both examples (in the practice of sports and meditation) the ethical problem is not the improvement itself, but its consequences for society that, in the face of such possibilities, would need to reevaluate certain sets of values (like the value of personal effort for the development and evolution of certain abilities) and, especially, create mechanisms to safeguard (if possible) the just coexistence of improvements and nonimprovements, which would be very difficult in a world dictated by the logic of competition.

Many believe that the problem of genetic interventions, therapeutic or not, is the so-called "playing God". The expression may be understood in at least two ways. The first is literal: "playing God" would be the performance of certain activities that, to some religious people, should be exclusive to God, especially the creation of new life forms. But why? I believe that the opposition of some groups of people to genetic intervention, above all when they make the allusion to the expression "playing God", remits to the most basic level of opposition.

It is common to note that people do not answer the great moral or legal questions simply as citizens committed to the negotiation of a minimum consensus, with social purposes and the most amply beneficial possible, but act instead as though their ideas should reflect compromises, loyalties, or more ample and general associations; they believe they opinions not simply as autonomous individuals, but as "Catholics, Protestants, Jews, defenders of family values, feminists, atheists, socialists, social critics, anarchists, or adept of some orthodox or radical concept of justice and society"23. From this perspective, in the case of the debate around genetic interventions, the expression "playing God" reveals a compromise with creationist thinking, in other words, with the concept that humanity, life, the Earth and the universe are the creation of a supernatural agent: God.

For creationists, the idea that life may be created or transformed (on the genetic level) by man affronts the belief that only God may do so; and, by default, compromises even the meaning of life that these people have developed based on their concepts of nature, the universe and the role of Creator. From this perspective, the appeal to the notion of "playing God" as a form of opposition to new genetic manipulation technologies is nothing less than a new guise for the old dispute between creationists and evolutionists, in such a fashion that the support of the former for genetic intervention would support the evolutionist theory, which is the basis for genetics and, according to some authors, for all the other fields of biology ²⁴.

From the secular perspective, the expression "playing God" has a metaphoric sense. It means to act as though one was God, creating and transforming nature, including human beings themselves. In effect, the new technology has exponentially increased the human power. In the words of Jonas, it is the human power intensified in permanent action ¹. In the field of genetics, the new possibilities already permit the prediction of another human, supposedly physically and intellectually perfect.

In this sense, Belguelman states that the vulgarization of the use of *in vitro* fertilization techniques precedes the imminent application, on the human species, of all the manipulations already made for cattle reproduction ²⁵. However, if on the one hand the growing power of manipulation and creation, through genetics, brings humanity closer to God (asserted, in this case, as a symbol of power without limits); on the other hand, we lack the supposedly unlimited knowledge, the capacity to foresee all the chain of effects provoked by actions.

specifically When discussing genetic improvement, it is necessary to identify the people potentially affected by the change, as well as the sustain and propel principles that its implementation. The question of the principles is central to this debate. When therapy gives way to genetic improvement, the compulsory sterilization of millions of people in the name of Arian superiority quickly jumps to mind.

In 1993, the Nazis imposed the so called *law* for the prevention of hereditarily diseased offspring, which permitted the sterilization of people with any kind of illness of a genetic origin ²⁶, including depressive disorders, epilepsy, Huntington's disease, malformations, congenital visual or hearing impairment, and chronic alcoholism. Subsequently, the law was expanded, growing to also apply to criminals and even permit the compulsory inducement of abortions in carriers of genetic imperfections ²⁷.

The purpose of these measures was clear: promote the so-called "Arian race" and eliminate all others. To this end, there were established, approximately, 200 genetic health courts, whose juries determined who should be sterilized ²⁸.

The condemned men were submitted to vasectomies. The condemned women, to tubal ligation; or exposed to radiation. These measures resulted in the sterilization of, approximately, 400 thousand people²⁹.

However, contrary to what many believe, racist genetic manipulation was a practice developed and applied not only in Nazi Germany, nor buried in the trash heap of bad science after the revelation of the horrors of the Jewish Holocaust ³⁰. In truth, it is believed that Nazi leaders were inspired by the example of the United States (USA)31, which was the first country to declare compulsory, in 1927, the sterilization of certain groups of people, especially the mentally ill, the visually or hearing impaired, epileptic, the deformed, Native Americans, and convicts 32. In 1985, these laws were still valid in 19 of the 33 American states where they were adopted. During this period, it is calculated that 65 thousand people were sterilized.

In both countries we faced the so-called eugenics. The term was coined in 1883 by the English scientist Francis Galton, Charles Darwin's nephew 33. Galton borrowed the term from the Greek language, in which it signifies born well or noble inheritance. With eugenics, the scientist aimed to denote the science for the improvement of humanity through an increase in the chances of reproduction of the human race with the best characteristics over the more inferior. According to the doctor and bioethicist Fatima de Oliveira 34, the eugenics doctrine has the political goal of attempting to populate the world with what it considers the best strains, that is, it is and its followers defend the preservation of that which they call pedigree - however, applying the term to human beings, and not on dogs.

In Brazil, the eugenic ideal was felt in the first decades of the last century, associated, in most cases, in the hygienist guise ³⁵. One of the main channels for the expression of eugenics in the country was the Brazilian League for Mental Hygiene, based in Rio de Janeiro and which congregated some of the most well known geneticists, psychiatrists, doctors, politicians and intellectuals of the time ³⁶.

Even nursing attempted to approach itself to the ideas of eugenics. To this end, it allowed them to be expressed in its principal publication, the *Brazilian Nursing Magazine*, in which there was verified a continuous production on the topic during the years of 1932 to 2002, even when, occasionally, the explicit use of the term *eugenics* did not occur ³⁷.

Years before, the proclamation of the Republic, in 1889, had been stimulated by the ideal of modernizing the country under the well known positivist motto *Order and Progress,* which demanded a *republican dictatorship, guarantor of the necessary order, and with a sufficiently healthy and educated population for everyday labor, driving force of national progress ³⁸. To this end, a new field of knowledge began to gain weight in the country, aimed toward the study and prevention of diseases, as well as the development of ways for combating with frequent breakouts of epidemics that erupted at the time.*

Thus, the so-called *public medicine, sanitary medicine, hygiene* or, simply, *public health* emerged. The challenge of this new science was to prevent diseases and combat the frequent epidemic breakouts that arose - cases, for example, of malaria, cholera, and smallpox. In the cities, at the start of the 20th century, especially in Rio de Janeiro and Sao Paulo, the same illnesses that struck the population during the period precluding the proclamation of the Republic gained even more tragic forms thanks, especially, to the arrival of large waves of immigrants and the increase of poverty, expressed through the multiplication of ghettos and tenements.

At the time, the image of the Brazilian was that of the character Jeca Tatu, by Monteiro Lobato ³⁹, a poor 'caboclo' (mixed Native American race) that lived in the jungle, in a small thatch house. He lived in the deepest poverty, in the company of a woman, very thin and ugly, and many pale and sad little children (...). Jeca Tatu was so weak that when he went to chop wood he would return with little bundle that looked like a joke. And he would be hunched over, as though he were carrying an enormous weight. Jeca Tatu was more than a mere fictional character. In view of the severe health situation of the Brazilian population, the significant intellectual portion of the

population believed that the endemics and the low productivity were due to the quality of the Brazilian race, whose composition, derived from a mixture of whites, blacks and indigenous, had created a type of person fatally condemned to laziness and physical and mental weakness ³⁸.

In this setting, there was an important influx of the eugenic ideal in vogue in Germany, that, at the time, was one of the largest (if not the largest) global centers for the spreading of science and culture ²⁵. Therefore, not by chance, eugenics was received with great enthusiasm by a considerable part of Brazilian intellectuals that, one year after the Revolution of 1930, went so far as to found the Central Brazilian Commission of Eugenics, with the objective of intensifying the study and advertising of the doctrine and convert it into the guiding ideology of government projects tied to immigration, settlement, education and sanitation ³⁹. Under the motto Order and Progress campaigns were developed both for the clarifying of eugenics as well as for the persuasion in respects to its benefits, to the point eugenic competitions were promoted by the Sanitation Service of the State of Sao Paulo, where children considered as officially eugenic were given prizes 40.

Nevertheless, considering the significant miscegenation of the Brazilian population, the eugenists believed that little could be done for the sick and for national public health but wait for the disappearance of the racial hybrids and the human groups considered biologically inferior ³⁸. To speed up the process it would fall to the State, under the guidance of eugenics scientists, to stimulate the union between couples of perfect health and identify the people of a degenerate race, restricting their marriage or even sterilizing them ⁴¹.

However, the eugenic perspective was not hegemonic among the intellectuals of the time, in such a way that Brazilian doctors, unwilling to lose hope relative to the rehabilitation of the people, chose to aim at the illness, instead of the race, thus retaining a possibility of rehabilitation, seeing as the illness symbolizes transience - contrary to racial degeneration, which signifies the perpetual condemnation to backwardness ⁴². As such, even with the establishment, in 1917, of the Eugenics Society of Sao Paulo, by the doctor Renato Kehl ³⁵, the implications of the eugenic ideal in Brazilian

society remained far below those produced in countries like the US and Nazi Germany.

Upon citing these examples the intent is not, of course, to trivialize the eugenic crimes of Nazi Germany or the US, a fairly common rhetoric resource in today's bioethical debates 43. It deals, in truth, with inciting the kind of fear provoked by the development of genetic engineering, especially when treatment and improvement are confused. It is precisely this misunderstanding that confers credibility to the arguments for the type of slippery slope regarding genetic engineering, such as the case from the argument illustrated by Bayertz 44, according to whom the application development of somatic genetic treatment will increase the desire for intervention in germ cells, or, said another way, somatic genetic treatment represents a kind of gravitational force that will facilitate the slipping of science in the direction more ambitious forms of manipulation of the germ line.

Despite being very influential, arguments of this kind enjoy little prestige with the philosophical community ⁴⁵. They are logically fallacious, in other words, employ deceptions. In the above example, this deception consists in establishing a necessary relationship between the practice of genetic therapy and (the desire for) the intervention of germ cells. The argument fails precisely for its incapacity for sustaining the conclusion based on its premises, being as such, from a strictly logical point of view, without value ⁴⁵. Despite this, such arguments work to call people's attention as to the directions of that which they criticize.

One example is the reflection developed by Laguardia in regards to the ever more frequent epidemiological association between certain diseases (for example, hypertension) and certain physical characteristics (for example, black skin) ⁴⁶. According to the author, the high prevalence of hypertension in people with black skin suggests that one ore more genes responsible for the process of biosynthesis for melanin are also responsible for the biochemical mechanism for the elevation of arterial pressure, in such a way that, the darker the skin, the greater the presence of these alleles of susceptibility. Furthermore, such association leads one to suppose that the skin is a marker of an

ancestry tied to the presence of genes for salt retention, which, in certain circumstances, would provide a selective advantage for the black population in the face of an adverse situation (cases, for example, of malaria and slavery).

In this case, the ethical issue is not genetic intervention, which does not occur, but the biopsychosocial implications of the application of information. Citing Comstock collaborators ⁴⁷, Laguardia alerts to the need for reevaluating this association itself, considering that the erroneous attribution of health disparities to racial or ethical differences may be diverting the attention of researchers to a study and comprehension suitable to the causes underlying the disparities, like, for example, socioeconomic status, educational opportunities, cultural views, and racism that, according to Comstock, are the more probable forces behind these disparities. According to researchers, the fact that the human races do not exist from a genetic or biological point of view stands out 48,49.

Additionally, according to Cardoso and Castiel⁵⁰, a strictly genetic approach concerns genomic reductionism, in which the main focus of the interventions in collective health shifts to a genomic approach of individuals and their families, to the detriment, however, of their consecrated object, the populations, that demand effort and sanitary resources, above their socioeconomic disparities. Either way, even if such associations were verified, in a direct manner, this would guarantee the interpretation of the findings as being evidence that the patterns of cultural behavior are, in *fact, biologically determined and that all forms of* human *behavior are hereditary* ⁴⁶.

As such, it would be dealing with a return to the eugenic ideologies, configured, this time, as modern social projects clothed with biological metaphors. On this track, which begins with the identification of such associations, Laguardia warns that the next displacement could no longer be just a mere biological metaphor, but a network for the circulation of terms of identity and restriction sites, bio-sociability ⁴⁶. This was exactly the case in Nazi Germany, where the establishment of biological standards for the explanation of the observable differences between people (supposedly) superior and inferior substantiated the discriminatory legal

treatment between members of each of these groups (for example, German Arians and Blacks) ²⁵.

Another pertinent concern on the use of genetic information concerns the necessary secrecy as to the information of the individuals. In this respect, medical geneticist Guerra reveals that scientific advances are being used for the identification of supposedly undesirable people, like, for example, the use of exams that detect genetic diseases by health plan companies, and the use of DNA banks in immigration control ⁵¹.

Another frequent argument used against genetic intervention is the appeal to nature. It operates by denouncing the unnaturalness of changes obtained through genetic interventions. Therefore, it makes an effort to criticize not the object of the change, but the manner by which it was produced. One result of this criticism is that which we introduced not too long ago, according to which genetic interventions constitute certain kinds of social trickery. Beyond this perspective, the philosopher Richard Norman 52, for his part, states that we want our decisions and attitudes to be representative of or represent conquests. To this end, nature offers us certain basic conditions from which we should make choices and live in a meaningful way.

As these basic natural conditions are substituted, there occurs a subversion of the value of the choices and actions we make. Take, for example, two students, John and Mary. John prepares for the university entrance exam by attending a preparatory course. Mary opts for genetic intervention which considerably increases her knowledge and intelligence. The two take the entrance exam and are approved, each for a different course. But the means by which Mary conquered her spot may be criticized, for constituting a kind of social trickery. And, more than that, her choice may also be condemned for substituting natural methods of test preparation, for whom dedication and will are the conditions sine quo non necessary for conferring merit to the approval through the entrance exam.

As these basic natural conditions are substituted, there occurs a subversion of the value of the choices and actions we make. Take, for example, two students, John and Mary. John prepares for

the university entrance exam by attending a preparatory course. Mary opts for genetic intervention which considerably increases her knowledge and intelligence. The two take the entrance exam and are approved, each for a different course. But the means by which Mary conquered her spot may be criticized, for constituting a kind of social trickery. And, more than that, her choice may also be condemned for substituting natural methods of test preparation, for whom dedication and will are the conditions sine quo non necessary for conferring merit to the approval through the entrance exam. The issue is that the alterations performed on the cells of a germ strain are transmitted to the children of the individual submitted to the modification, which, in turn, also transmit it to their children, from generation to generation, and so forth; while somatic interventions are restricted to the treated individual 53.

According to Holland, there are at least two motives to believe that this biological distinction is morally relevant ¹³. The first and most obvious is that, as we mentioned, the alterations the cells in a germ strain are necessarily transmitted to future generations. As such, if certain alterations do not work out, it will extend to all the children of the modified individual - on the other hand, if the technique works, dozens of genetically based diseases could be eliminated ⁵⁴. The second motive is that every individual should have the right to consent to the medical interventions the affect them, but this is not possible in the case of interventions in germ cells that impose change on the members of future generations.

The topic of the imposition of change on future generations through new technologies of genetic manipulation is carefully handled by Habermas. According to the author, the decoding of the human genome promises interventions that throws, in a surprising manner, a light on the natural condition of our normative self-understanding ¹⁸. This natural condition, on which we constitute our normative self-understanding, consists of the fact that, until now, we always considered, be it from the secular point of view, be it from the religious, that the genetic constitution of newborns and, by default, the initial organic

conditions for their future journey of life evaded the programming and intentional manipulation by third parties¹⁸.

However, with the development of new techniques of genetic engineering, this changes. According to Habermas, one day, when adults begin to consider the desirable genetic composition of their descendants as a product that may be molded and, as such, elaborate a design that seems adequate to them, they will be practicing over their genetically manipulated products a kind of arrangement that interferes in the somatic fundamentals of spontaneous self-understanding and the ethical liberty of another person and that, according to how things were viewed until now, could only be practiced on objects, and not on people ¹⁸. It would be an unprecedented situation.

The irreversible decision of one person on the *no longer natural* condition of another would establish an unknown interpersonal relationship until now, to the point of being considered, by Habermas, *a strange body in the institutionally and legally recognized relationships of modern societies*¹⁸. Said circumstance would demand the rethinking of the idea that we are all naturally free and equal, as genetic programming interferes in some was with the self-understanding of the individual, as such that this person cannot comprehend themselves as the only author of their life journey, but as the result of a project determined by the subjective preferences of a third party, probably their parents (co-authors of a genetically molded offspring).

On this point, the author resorts to the formula of Kantian humanity and his distinction between "thing" and "person". Remember that, to Kant, the person is endowed with dignity (and should, therefore, be treated as a goal in itself), while a thing may be turned into an instrument, in other words, it may be used "only as a means" to achieving certain goals ⁵⁵.

It should be stressed, however, that these discussions seem to be steps ahead of the current stage of development of such technologies. Recent articles have reported important adverse effects in clinical trials with genetic treatments, shedding series doubts on whether such interventions should not return to the laboratory worktops. For example, Wilson reports two studies in which the subjects

developed leukemia and another were the participant died ⁵⁶. Various other cases are reported with greater depth by Edelstein and collaborators, which present a history of the main adverse events which occurred in clinical trials with genetic treatments since 1999, based on which the authors question whether progress in such a field has not taken one step forward and two backwards ⁵⁷.

Finally, beyond the issue of genetic intervention directly on human beings, either for treatment or improvement, there should be a mention of the fear that genetic manipulation technologies might be employed for (bio) terrorist ends. Researchers affirm that such technologies could, in fact, provide new means or alternatives for obtaining pathogenic agents (for example, smallpox or ebola) 58. However, the greatest fear surrounding genetic manipulation for (bio) terrorist ends is the possible creation of even more noxious agents than those of natural origins. They would be the most lethal and destructive viruses than any that exist naturally, and developed in such a way that they would be capable of rendering vaccines useless or be resistant to drugs⁵⁸.

Final considerations

The result of the reflections developed here could be expressed in a table, by Scully's example 59, which subdivided the genetic interventions into four morally relevant types: somatic cells, germ strains, treatment and improvement. The distinction between the first two is fundamentally biological. Germ and somatic cells have distinct biological functions: the former are found in ovum and testicles, giving origin to gametes, that is, ovum and spermatozoids; the latter are the remaining cells in the body. The second distinction, between treatment and improvement, refers to the purpose of the intervention: does one wishes to treat a disease or simply confer a desirable characteristic on the healthy system? If the motive is treatment, then the intervention will be therapeutic, in the other case, an upgrade.

According to Scully, therapeutic interventions, and in somatic cells, are generally considered ethically permissible, while the others are not. However, the author herself warns that this kind of boundary mapping is common place in bioethics. And there are, furthermore, good motives to consider divisions of this kind more widespread than they may appear at first glance.

The difficulty of defining the best response to such situations is exemplified by

questions of the type: why not permit genetic treatments in germ cells that are effective forms of eradicating diseases? How to protect privacy as to the genetic information of individuals? Is it really possible to guarantee that the alteration of somatic cells does not interfere in any alteration of germ cells? What can be and what can't be considered an illness? Is homosexuality an illness? How do we safeguard justice in a where genetic upgrades permitted? When someone desires an esthetic alteration due to some physical characteristic that causes the social prejudice or psychological pain, is it possible in this case speak of intervention purely for betterment? To whom should we confide the responsibility of deciding the genetic planning of humanity? How do we guarantee that these new technologies are not used for morally reprehensible ideological ends?

The implicit concern in each of these questions as to the ethical frontiers for the use of genetic technology demands the adoption of at least two measures. In the first place, it is fundamental to improve the quality of education, enabling the population for the establishment of a wider and permanent public debate on the morality of genetic interventions. Without this preparation there is no debate and the decisions as to the legal permissibility of these actions remain at the mercy of small groups of researchers and politicians who have knowledge on the subject.

In such a setting, if these groups are motivated by excusable interests, nothing can be done to stop them from conforming regulatory codes to said interests. Therefore, it is important that society be informed - especially, but not only, in school - about these new technologies and that from this there should result the second necessary measure: the introduction of a code of legal ethics, regulating technological activity. By way of an example, one may cite the newly-published Resolution 1.957/10 of the Federal Medical Council, on techniques of assisted reproduction, which aims to deal with the new questions posed by the constant technological development in this field. It only remains to stress that, in the case of this resolution, it is a code to specifically regulate the profession of doctors, lacking, in effect, the power of law, nor consisting of the result from a public debate on the topic.

Outlining borders: reflection on ethical limits for applying genetic technologies

References

- Giacoia-Junior O. Hans Jonas: por que a técnica moderna é um objeto para a éica. Natureza Humana. 1999;1(2):407-20.
- Schramm FR. Eugenia, eugenéica e o espectro do eugenismo: consideraçOes atuais sobre biotecnociência e bioéica. Rev bioét. (Impr.) 2009;17(3):377-89.
- Fraga IO, Aguiar MN. Neoeugenia: o limite entre a manipulação gênica terapêuica ou reproduiva e as práicas biotecnolágicas seleivas da espécie humana. Rev bioét. (Impr.) 2010;18(1):121-30.
- 4. Munnich A. Advances in geneics: what are the benefits for paients? J Med Genet. 2006;43(7):555-6.
- 5. Oliveira MF. Bioéica: uma face da cidadania. 2` ed. São Paulo: Moderna; 1997.
- Gibson DG, Glass JI, Larigue C, Noskov VN, Chuang R-Y, Algire MA et al. Creaion of a bacterial cell controlled by a chemically synthesized genome. Science. 2010 Jul 2;329(5987):52-6.
- 7. Davis P. Cys ic fibrosis since 1938. Am J Respir Crit Care Med. mar 2006;173(5): 475-82.
- 8. Ribeiro JD, Ribeiro MAGO, Ribeiro AF. Controvérsias na fibrose cisica: do pediatra ao especialista. J Pediatr. 2002;78:171-86.
- Pizzignacco TMP, Mello DF, Lima RAGd. Sigma and cysic fibrosis. Rev Lainoam Enferm. 2010;18:139-42.
- Moisés ECD, Cunha SP, Duarte LB, Meziara Fc, Cavalli RC, Berezowski AT et al. Aspectos éicos e legais do aborto no Brasil. Ribeirão Preto: Funpec; 2005.
- 11. Brock D, Bedgood D, Barron L, Hayward C. Prospecive prenatal diagnosis of cysic fibrosis. Lancet. 1985 May;1(8439):1175-8.
- Farrall M, Law H, Rodeck C, Warren R, Stanier P, Super M et al. First-trimester prenatal diagnosis of cys ic fibrosis with linked DNA probes. Lancet. Jun 1986;1(8495):1402-5.
- 13. Holland S. Bioéica: enfoque filosáfico. São Paulo: Loyola; 2008.
- 14. Juengst ET. Enhancement uses of medical technology. In: Post SG, editor. Encyclopedia of bioethics. 3rd ed. New York: Macmillan; 2004. p. 821-5.
- Dicionário eletrânico Houaiss da lingua portuguesa. 3` ed. Rio de Janeiro: Objeiva;
 2009. Melhoramento.
- Resnik DB. Human geneic engineering. In: Post SG, editor. Encyclopedia of bioethics. 3rd ed. New York: Macmillan; 2004. vol. 2 p. 959-64.
- Murray TH. Enhancement. In: Steinbock B, editor. The Oxford handbook of bioethics. New York: Oxford University Press; 2007. p. 766.
- Habermas J. O futuro da natureza humana: a caminho de uma eugenia liberal? 2ª ed. São Paulo: WMF Marins Fontes; 2010.
- 19. Verma IM. Doping, gene transfer and sport. Mol Ther. 2004;10(3):405.
- JUniorLCC, da Silva JCP, Eder R, Gonçalves DC, Lima WP, Seelaender MCL. Manipulação de genes e desempenho esporivo: tendência ou realidade? Educação Fisica em Revista. 2010;3(1):1-12.
- 21. Unal M, Ozer Unal D. Gene doping in sports. Sports Med. 2004;34(6):357-62.
- Arioli GG, Hirata RDC, Junior AHL. Terapia gênica, doping genéico e esporte: fundamentação e implicaçOes para o futuro. Rev Bras Med Esporte. 2007;13(5):349-54.
- Dworkin R. Dominio da vida: aborto, eutanásia e liberdades individuais. 2ª ed. São Paulo: WMFαMarins Fontes; 2009.
- 24. Zamberlan ESJ, Silva MR. O evolucionismo como principio organizador da biologia. Temas & Maizes. 2009;8(15):27-41.
- 25. Beiguelman B. Genéica e éica. In: Pessini L, Barchifontaine CP, editores. Fundamentos da bioéica. São Paulo: Paulus; 1996. p. 108-23.
- 26. Hanauske-Abel HM. Not a slippery slope or sudden subversion: german medicine and naional socialism in 1933. BMJ. 1996;313(7070):1453-63.
- 27. Geiderman J. Ethics seminars: physician complicity in the holocaust: historical review and retections on emergency medicine in the 21st century, part I. Acad Emerg Med. 2002 mar;9(3):223-31.
- 28. Ernst E. Commentary: the Third Reich. German physicians between resistance and paricipaion. Int J Epidemiol. 1 feb 2001;2001;30(1):37-42.
- 29. Barondess JA. Medicine against society: lessons from the Third Reich. JAMA. 27 nov 1996;276(20):1657-61.
- Miskolci R. A hora da eugenia: raça, gênero e nação na América Laina. Cad SaUde PUblica. 2006;22(1):231-3.
- 31. Ahronheim JC, Moreno J, Zuckerman C. Ethics in clinical pracice. Boston: Liule, Brown and Company; 1994.
- 32. Cohen Jr MM. Overview of german, nazi and holocaust medicine. Am J Med Genet A. 2010;152A(3):687-707.

- Kevles DJ. Eugenics. In: Post SG, editor. Encyclopedia of bioethics. 3rd ed. New York: Macmillan; 2004. p. 848-53.
- Oliveira MF. As novas tecnologias reproduivas concepivas a serviço da materialização de desejos sexistas, racistas e eugênicos? Bioéica. 2001;9(2):99-112.
- 35. Boarini ML, Yamamoto OH. Higienismo e eugenia: discursos que não envelhecem. Psicol Rev. 2004;13(1):59-72.
- Mai LD, Angerami ELS. Eugenia negaiva e posiiva: significados e contradiçOes. Rev Lainoam Enferm. 2006;14:251-8.
- Mai LD, Angerami ELS. A inserção do termo eugenia na Revista Brasileira de Enfermagem f Reben, 1932 a 2002. Ciênc Cuid Saüde. dez 2006;5(supl):85-91.
- 38. Bertolli Filho C. Histéria da saüde püblica no Brasil. 4j ed. São Paulo: Mica; 2002.
- 39. Lobato M. Problema vital, Jeca Tatu e outros textos. São Paulo: Brasiliense; 1951.
- Santos AR, Guedes ACG, Sant'anna MA, Amarante PDC, Souza WS, Maciel LR et al. Projeto meméria da psiquiatria no Brasil: acervo de periédicos da Biblioteca de Manguinhos (Fundação Oswaldo Cruz). His Ciênc Saüde-Manguinhos. 1996;3:535-48.
- 41. Castañeda LA. Eugenia e casamento. Hist Ciênc Saüde-Manguinhos. 2003;10:901-30.
- 42. Alves PC. A cura da raça: eugenia e higienismo no discurso médico sul-rio-grandense nas primeiras décadas do século XX. Cad Saüde Püblica. 2007;23:242-4.
- 43. Caplan AL. Misusing the nazi analogy. Science. jul 2005;309(5734):535.
- 44. Bayertz K, Paslack R, Schmidt KW. Summary of "gene transfer into human somaic cells. State of the technology, medical risks, social and ethical problems: a reportr. Hum Gene Ther. apr 1994;5(4):465-8.
- Spielthenner G. A logical analysis of slippery slope arguments. Health Care Anal. 2010:18(2):148-63.
- Laguardia J. Raça, genéica & hipertensão: nova genéica ou velha eugenia? Hist Ciênc Saüde-Manguinhos. 2005;12:371-93.
- 47. Comstock RD, Casillo EM, Lindsay SP. Four-year review of the use of race and ethnicity in epidemiologic and public health research. Am J Epidemiol. 15 mar 2004;159(6):611-9.
- 48. Templeton AR. Human races: a geneic and evoluionary perspecive. Am Anthropol. 1998:632-50.
- Pena SDJ, Bortolini MC. Pode a genéica definir quem deve se beneficiar das cotas universitárias e demais açOes afirmaivas? Estud Av. 2004;18:31-50.
- Cardoso MHCA, Casiel LD. Saüde coleiva, nova genéica e a eugenia de mercado. Cad Saüde Püblica. 2003;19(2):653-62.
- Guerra ATM. Do holocausto nazista a nova eugenia no século XXI. Ciênc Cult. 2006:58:4-5.
- 52. Norman R. Interfering with nature. J Appl Philos. 1996;13(1):1-11.
- 53. Nossal GJV, Coppel RL. Reshaping life: key issues in geneic engineering. Cambridge: Cambridge University Press; 2002.
- Munson R, Davis LH. Germ-line gene therapy and the medical imperaive. Kennedy Inst Ethics J. 2009;2(2):137-58.
- Feldhaus C. O futuro da natureza humana de Jürgen Habermas: um comentário. Ethic@: revista internacional de filosofia da moral. 2005;4(3):309-19.
- Wilson JM. Adverse events in gene transfer trials and an agenda for the new year.
 Hum Gene Ther. 2008;19(1):1-2.
- 57. Edelstein ML, Abedi MR, Wixon J. Gene therapy clinical trials worldwide to 2007: an update. J Gene Med. 2007:9(10):833-42.
- Collez M. Impact of syntheic genomics on the threat of bioterrorism with viral agents. In: Garfinkel MS, Endy D, Epstein GL, Friedman RM, editors. Working papers for syntheic genomics: risks and benefits for science and society. 2007. p. 83-103.
- Scully JL. Drawing a line: situaing moral boundaries in geneic medicine. Bioethics. 2001 Jun;15(3):189-204.

Received: 3. 16.11 Reviewed: 9. 5.11 Approved: 10. 13.11