RESEARCH ARAŞTIRMA

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Ethical Limits of Academicians in Europe to Genetic Practices and Eugenics: Case Study

Avrupa'daki Akademisyenlerin Genetik Uygulamalar ve Öjeni Konusunda Etik Sınırları: Durum Çalışması

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ABSTRACT The 20th century has been a period in which studies on genetics have intensified and important applications have been experienced. In this study, it is aimed to reveal what academics think about the potential of the concept of "design babies", which is a result of biotechnological applications, to cause eugenics. For this purpose, data were collected with the "scenario-based form" titled eugenics developed by the researcher. This questioning was carried out over the issue of changing the genetic characteristics of a baby before birth with the applications brought about/will be brought about by genetic engineering technologies. The research was carried out with 14 academicians working at Charles University in Czechia. Mixed content analysis was performed on the data obtained by applying the scenario form via the internet. As understood from the findings, the approaches of Czech academicians to the issue of gene editing revealed on the basis of the concept of "designer babies" are ethically negative. It is understood that it is not found ethical by the participants because of reasons such as the concern that possible gene editing will not be equally accessible to all people, causing discrimination and commercial abuse and not being able to predict what kind of problems the gene interactions that may result from the interventions may cause in the future. As a result, it is understood that the idea of creating the perfect breed to create more beautiful, smarter and more qualified people is wrong, and therefore they think that eugenic goals such as creating a superior human race are dangerous.

Keywords: Genetic practices; ethics; eugenics; designer babies; biotechnology

ÖZET 20. yüzyıl genetik üzerine çalışmaların yoğunlaştığı ve önemli uygulamaların yaşandığı bir dönem olmuştur. Bu çalışmada akademisyenlerin, biyoteknolojik uygulamaların bir getirisi olan "tasarım bebekler" kavramının öjeniye neden olma potansiyeli hakkında ne düşündüklerini ortaya koymak hedeflenmektedir. Bu amaçla veriler, araştırmacı tarafından geliştirilen öjeni başlıklı "senaryo temelli form" ile toplanmıştır. Bu sorgulama ise genetik mühendisliği teknolojilerinin getirdiği/getireceği uygulamalarla bir bebeğin doğumdan önce genetik özelliklerinin değiştirilmesi üzerinden gerçekleştirilmiştir. Araştırma Çekya'da Charles Üniversitesinde görev yapan 14 akademisyen ile gerçekleştirilmiştir. İnternet yoluyla senaryo formunun uygulanması ile elde edilen veriler üzerinde karma içerik analizi gerçekleştirilmiştir. Akademisyenlerin, "designer babies" kavramı üzerinden gen düzenlemeleri konusuna olan yaklaşımları etik açıdan olumsuzdur. Yapılması muhtemel gen düzenlemelerinin tüm insanlar tarafından eşit bir şekilde erişilemeyeceği kaygısı başta olmak üzere, ayrımcılığa yol açma, ticari suistimale neden olma, yapılacak müdahalelerle oluşabilecek gen etkileşimlerinin gelecekte ne gibi sorunlara yol açabileceğinin tahmin edilememesi gibi nedenlerden dolayı katılımcılar tarafından etik bulunmadığı anlaşılmaktadır. Sonuç olarak akademisyenlere göre daha güzel daha zeki daha nitelikli insanların oluşturulmasına yönelik mükemmel ırka erişme fikrinin yanlış olduğu, dolayısıyla üstün insan ırkı oluşturmaya yönelik öjeni hedeflerinin tehlikeli olduğu görüşünde oldukları anlaşılmaktadır.

Anahtar Kelimeler: Genetik uygulamalar; etik; öjeni; tasarım bebekler; biyoteknoloji

ADVANCES IN BIOTECHNOLOGY

Through recombinant DNA technology, it has been possible to manipulate the hereditary materials in the cells of different organisms by creating new combinations of characters and functions that could not be obtained with conventional methods before. These rDNA technology and genetic engineering applications have started to contribute to the diagnosis and

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treatment of hereditary defects, serious diseases, the development of new biopharmaceutical drugs, vaccines, and the elimination of hereditary diseases as a branch of modern science, creating profound effects in the field of medicine.[1]

EMERGENCE, GOALS AND ETHICAL ASPECTS OF HUMAN GENOM PROJECT

When genetic science and biotechnology are examined in the context of protecting human health and increasing the quality of life, it can be said that promising studies have been carried out for the future. It has many important goals such as detecting the genes that cause disease in humans, replacing these genes with healthy genes, determining the susceptibility to many genetic diseases that cannot be cured today, and developing drugs suitable for the genetic structure of humans.[2-4]

EUGENICS

Although the application areas of genome editing are quite wide, it is known to have three important goals when examined in the context of human medicine. The first of these goals is related to the prevention and treatment of diseases, and it is predicted that paediatric and internal diseases such as cancer types, infectious diseases, classical hereditary diseases, progressive muscular dystrophy (Duchenne), Huntington's, cystic fibrosis can be treated or prevented. Secondly, the CRISPR/Cas9 method offers new possibilities in the field of reproductive medicine and has the potential to treat genetic defects that cause infertility with germline therapy in the future. Third, genome editing has the potential to be used for enhancement; that is, for optimizing genetic traits. At this point, the potential of human genom project for enhancing human characteristics and abilities in a way to form the ground for "creating privileged people" is one of the main concerns. At first glance, if we consider that "the demand for genetic superiority" includes applications to eliminate diseased and defective genes, we can think that this is a very natural demand. However, the real danger will begin when this demand is followed by further demands such as wanting to be smarter, more handsome, taller, stronger etc.[2] How far will individuals go when they are allowed to decide on eye colour, gender, intelligence capacity, etc. of the embryo and who will set the limits? In this case, human beings will undoubtedly try to exceed their limits wherever possible to foster their interest. These demands lead us to the concept of "eugenics (innate well-being - creating a privileged person - hereditary nobility)" [2].

THE IMPORTANCE AND THE AIM OF THE STUDY

It is very important for individuals to make informed decisions that have passed through the filter of values and in accordance with ethical principles. Undoubtedly, family, environment and academic life function as a whole in making decisions in accordance with ethical principles and prepare the individual for the future. This situation necessitates that individuals who are educated in fields such as medicine, molecular biology and genetics, science education and biology education should be well-equipped in terms of professional ethical principles. Therefore, at this point, universities and academicians have important responsibilities. In addition to cognitive goals, universities also have affective goals that students should accomplish. Universities have an important place in transferring the values necessary for the healthy continuation of social relations to students, and it is important to decide which values to be imparted to students. In this respect, if the concept of individual ethics is handled well, people can be made compatible with the concept of world citizenship in the 21st century. For this reason, the effects of academicians on their students and their attitudes guiding the society will be effective in making ethical decisions in the dilemmas that individuals have been/will be exposed to primarily in professional fields. While this is the case, it is important to determine the ethical views of the academicians who train the relevant professional groups of the society and to witness their discussions on eugenics. In the current study, it is aimed to reveal what academicians think about the potential of the concept of "designer babies", which is a result of biotechnological applications, to cause eugenics and to determine what kind of an ethical judgment process they pass their opinions through. Thus, an answer to the question "What are the ethical views of academicians in Central Europe on eugenics?" will be

sought in this study. In this connection, the participating academicians will be asked the following questions to elicit their general opinions on the issue of eugenics; 1) Is the effort to create a genetically perfect breed and eliminate defected genes ethically appropriate? 2) Which genetic applications are acceptable and which are not? 3) If a restrictive hereditary disease is detected by prenatal testing, would you rather have your own baby born or not? 4) Can you give an example of positive and negative eugenics? 5) How do you define eugenics? 6) What are your ethical concerns on the issue of eugenics.

MATERIAL AND METHODS

RESEARCH DESIGN

Case study, one of the qualitative research designs, was used in this study. The study was designed to be conducted at Charles University in Czechia, a Central European country. The study was carried out with the participation of 14 academicians by questioning the ethical aspects of genetic engineering applications through the concept of "designer babies" and the potential of these applications to cause eugenics.

DATA COLLECTION TOOLS

Data collection tool in the study, a scenario form titled "Eugenics" was used to get the opinions of the participants about the ethical dimensions of genetic applications and their potential to cause eugenics. In the scenario-based form, 7 semi-structured questions were included after the scenario and the participants were questioned about the potential of genetic applications to discriminate on people in the future and whether this situation would turn into a desire to "create a superior human being". This questioning was carried out over the issue of changing the genetic characteristics of a baby before birth with the applications brought about/will be brought about by genetic engineering technologies.

DATA ANALYSIS

Mixed content analysis was planned on the data obtained from the application of the scenario form via the internet and the semi-structured interviews.

RESULTS

In this section, the answers given by the participants to the data collection tool (eugenics scenario form) were analyzed with a mixed-method of content analysis. The answers given by the participants to the question whether the effort to create a genetically perfect race and the elimination of defective genes are ethically appropriate were examined. Approximately half of the participants stated that it is ethically appropriate to carry out these applications "in some cases". The following question in the "eugenics scenario form" was asked to the participants; "Which genetic applications are acceptable for you and which are not?, Please give examples." On the basis of the opinions expressed by the participants, the following 3 main categories were obtained in the main theme of "Acceptable genetic applications: "Gene modifications within the scope of medical intervention are acceptable", "Editing of defective genes is acceptable in a born human, not in embryos" and "No intervention in human genes is acceptable in any case". The following question in the "eugenics scenario form" was asked to the participants; "Suppose there is an inherited disease in your family that makes human life very difficult and restrictive. You want to know if your child has this disease, if the result is positive, would you prefer to terminate the embryo's life or to have the baby born? Why?" From the opinions expressed in this theme, 4 main categories were obtained: "Yes it should be born", "No, it should not be born", "I am not sure" and "It depends on the type of restriction". The following question in the "eugenics scenario form" was asked to the participants; "Can you give examples of positive and negative eugenics that you know or have heard so far?" Of the participants, 72% gave examples in the subcategory of "Pre-implantation and pregnancy screenings", 14% in the subcategory of "German "Pramen" Project", 14% in the subcategory of "Genetically modified babies Lulu and Nana" and 14% in the subcategory of "Taking soldiers into the army who have more muscle mass in some countries" for positive eugenics. Of the participants, 67% gave examples in the subcategory of "Sterilization of gypsies, homosexuals, race-centred genocides",

11% gave examples in the subcategory of "Nazi experiments", 11% gave examples in the subcategory of "Lebensborn project" and 11% in the subcategory of "Sparta's eugenic plans in Greek" for negative eugenics. The following question in the "eugenics scenario form" was asked to the participants; "What is your definition of "eugenics?" "Write your point of view on the subject of eugenics in detail." On the basis of the opinions expressed by the participants, the following 5 main categories were obtained; "It's a process that needs attention", "Deliberate genetic modifications on humans", "Genetic modifications to reach the superior human race", "Medical genetic applications are not eugenics" and "Definition is very difficult". The following question in the "eugenics scenario form" was asked to the participants; "What are your ethical concerns about eugenics in general?" On the basis of the opinions expressed by the participants, 4 main categories were obtained; "Discrimination", "Unpredictability of future results", "Intervention in the natural process" and "Possibility of abuse".

DISCUSSION

As understood from the findings, the approaches of Czech academicians to the issue of gene editing revealed on the basis of the concept of "designer babies" are ethically negative. It is understood that it is not found ethical by the participants because of reasons such as the concern that possible gene editing will not be equally accessible to all people, causing discrimination and commercial abuse and not being able to predict what kind of problems the gene interactions that may result from the interventions may cause in the future. In addition, it is understood that the idea of creating the perfect breed to create more beautiful, smarter and more qualified people is wrong, and therefore they think that eugenic goals such as creating a superior human race are dangerous. Rodriguez et al. conducted a study involving four Latin American countries (Argentina, Chile, Mexico and Peru), using lawyers, biomedical researchers, civilians, and scientific literature as samples.[5] This study has also revealed that there are concerns that gene editing may create genetic discrimination, about the risks of using genetic manipulations for eugenic purposes and the potential for genetic applications obtained will open a large commercial gap between developed and undeveloped countries. Academicians in Czechia largely do not support any intervention to human genes and do not find it ethical. However, they may argue that gene interventions are acceptable as far as genetic diseases are concerned. A certain part of the participants, on the other hand, consider gene interventions made to somatic cells, other than germline interventions, as acceptable. The group that does not support any genetic intervention insists on this view even if there is a human benefit. In addition, the participants strongly oppose any genetic intervention to produce desirable traits, including physical traits, on the embryo. Evsel, in his study on 120 people from Ankara, concluded that 49.2% of the participants supported the idea that genetic tests, which seemed more innocent and useful compared to eugenics applications, would be used to "increase the values of beauty and intelligence".[6] Rodriguez et al., on the other hand, concluded in their study that genetic information has the potential to be "used in order to increase values such as beauty and intelligence", with 16% of lawyers and 15% of scientists approving it.[5] Arslankara conducted a study on pre-service science teachers to question the importance of biotechnology.[7] The pre-service teachers stated that they strongly supported that parents should not be given the opportunity to determine the characteristics of their children to be born, however, developments in biotechnology increased their ethical concerns. The academicians participating in the study were positioned as parents of a baby with a genetic disease with a question item in the measurement tool. However, it was aimed to ensure that they were positioned as decision makers, not as observers. In this way, it was desired to understand whether their approaches to gene interventions would differ. The participants mostly exhibited an undecided attitude about whether a baby with a genetic disease should be born or not. It is understood that the fact that genetic disease restricts the baby's life and other emotional states have an effect on their state of being undecided. In the literature, this process can be summarized as follows. Today, preimplantation genetic diagnosis (PGD) can determine which embryos are affected by

which genetic conditions before implantation. This process ensures that only embryos free from hereditary diseases are transferred to the uterus by in vitro fertilization (IVF). While those that carry the harmful genes will be discarded prior to implantation. Currently, PGD and IVF have been used to prevent couples from giving birth to a child afflicted with genetic disease. This has created many concerns surrounding the possibility of these techniques being used to hand-select certain genetic traits for non-therapeutic reasons.[8] When the participants were asked to give examples of positive eugenics, it was understood that the majority of them gave genetic diagnosis and screening tests. A small part of them gave the concept of "designer babies" with the example of "Lulu and Nana", the German Pramen project, and the election of people with stronger muscle mass as soldiers in some countries. At this stage, some participants showed the "Lulu and Nana" as an example of positive eugenics, while others showed it as an example of negative eugenics. In the previous sections, it was underlined that the participants in the sample group found some genetic applications acceptable even if they did not support the intervention to human genes. It is understood that the participants who evaluated the example of Designer babies and Lulu and Nana under the heading of positive eugenics, may have thought in this way due to their potential to prevent diseases. The participant, who evaluated the same example under the heading of negative eugenics, detailed the reason behind this opinion in the "anything else to tell" section of the measurement tool. This point of view seems to be underlined by the belief that why there is a need for gene editing when there are many ways to avoid human immunodeficiency virus. When the other examples of negative eugenics given by the participants are examined, it can be seen that the sterilization operations that Gypsy women living in Czech lands are subjected to against their will even while they are using health care service for another reason, sterilization of homosexuals, all other race-centred genocides such as today's Chinese genocide against Uyghurs and especially Jewish genocides and Nazy experiments come to the fore. It is understood that the approach of the Czech society to gene interventions was drawn with such sharp boundaries because they witnessed the events of the Jewish genocide in the Nazi period and the sterilization of Gypsy women against their will and knowledge. Rodrigues et al. emphasize the need for strict legal measures to protect the human dignity and prevent the arbitrariness of using genetic manipulations.[5] When the participants were asked to define the concept of eugenics, it was understood that they mostly concentrated on the expressions "Deliberate genetic modifications on human" and "Genetic modification to reach a superior human breed". Based on these views, it is understood that they defined the concept of eugenics with the expression "Desired gene modifications to create a superior human breed". And this definition coincides with the literature explanation of the concept of eugenics, which means "hereditary nobility", "good birth" as a word, and looking for ways to raise suitable generations by making conscious studies in order to develop certain hereditary qualities.[9] This study is also important in terms of understanding how acceptable the beneficial properties of biotechnology are despite some risky applications in different societies, especially in societies that have been exposed to negative eugenic movements. It is understood that the participants in the sample group, who are members of the Czech society in Czechia, approach the subject cautiously in terms of risks, even if gene editing has beneficial effects. At this point, it seems that the negative eugenic movements they have experienced throughout history have a great effect on these attitudes. In addition to this, it is important to have sufficient information about the subject and to think deeply about all its positive/negative dimensions. In general, it is understood that the lack of information about the studies on the human genome and the lack of in-depth thinking cause concerns in the society.[5]

CONCLUSION

Academicians' approaches to ethical issues and their ethical thinking abilities are very important because of their important position in society, their guiding effects and especially their shaping effects on the thought processes of their student. Academicians' approaches to ethical issues and their ethical thinking

abilities are very important because of their important position in society, their guiding effects and especially their shaping effects on the thought processes of their students. In this regard, the study made the academicians in Czechia question the ethical dimensions of genetic applications and their potential to cause eugenics, while at the same time, it enabled them to enter a process that question the benefit/harm balance on the subject. In this direction, it is thought that an important contribution was made to them in terms of raising their awareness of the issue so that they can better serve to their students. It is thought that emphasizing the following issues in the suggestions to be made will contribute to the society and literature. First, questioning the potential of biotechnological applications such as gene editing and genetic manipulations to cause eugenics, thinking about it and discussing the ethical dimensions will contribute to the advancement of our future society on a solid ground. It is thought that especially the subject of "designer babies" is perceived as a negative eugenics movement due to its potential to create inequality and discrimination in society. It is known that the contribution of especially media news is great in this regard. At this point, it is necessary that the subject of genetic applications and eugenics should be discussed more today and that its legal boundaries should be drawn globally. Even though the subject may seem utopian to some segments of the society at present, it is obvious that in the near future, designer babies applications will be frequently discussed and implemented with its different dimensions. In this sense, although there have been painful examples of eugenics in the past, it is thought that the dimensions of gene editing to make human life healthier should be carefully emphasized. Therefore, drawing the legal boundaries well for all kinds of genetic applications will contribute to the smoother progress of the applications. The way to do this is to discuss the issue with all its dimensions by different disciplines and even to establish special commissions/boards in every society for this purpose. Therefore, being able to talk and discuss the subject of eugenics and ethics, to deal with all aspects that may be ethically problematic and to carry out research that contributes to the literature in this sense are very important issues in order to draw legal boundaries well. Although the conceptually sufficient literature on the subject was reached during the study, due to the small number of research articles, it was very difficult to find the literature through which the results obtained in the current study and the opinions expressed by the participants on the subject could be compared. Therefore, conducting research by scientists from different disciplines on the subject and their discussion of the subject, supporting it with research, presenting suggestions and revealing the general opinion in the society will facilitate the work of the above-mentioned and proposed commissions to be established and contribute to drawing legal boundaries.

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

This study is entirely author's own work and no other author contribution.

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