Viewpoint

The gene editing of human embryos and the new eugenics

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Introduction

The possibility of editing the genome of human beings has become significantly more likely with the development of systems such as CRISPR/Cas9 and the announcement, in 2015, that Chinese scientists had become the first to gene-edit a human embryo [1]. This would enable specific variants of genes to be edited by removing or inserting genetic material into a genome in order to address a number of genetic disorders.

From an ethical perspective, some general comments have already been made highlighting the many advantages and benefits to humankind arising from the possibility of manipulating the genes of a person [2].

However, there are also some concerns relating to safety. For example, inserting or deleting specific genes in the right place of the genome of a developing embryo without upsetting the biological equilibrium of the cell(s) is a difficult operation. A certain gene may influence a number of different characteristics which means that even if a gene was modified to influence a certain dysfunction this could give rise to unexpected consequences. The overall result would be a modification that may be less than beneficial [3].

More specific ethical arguments, however, concerning gene editing relate to the extent of the changes being contemplated and these will now be examined in turn.

Somatic gene editing

To begin with, if the editing takes place with the aim of addressing a genetic disorder on a mature embryo, foetus, child or adult (and not his or her descendants), this could be considered in a similar manner to already existing somatic gene therapy procedures which have generally been accepted by society. Such applications would then not raise many new significant ethical problems, apart from safety and efficacy.

Germline gene editing

Using gene editing with the aim of germline gene modifications (intentionally changing the genes of descendants), on the other hand, raises significant ethical concerns some of which were discussed in a report published in 2017 by the US-based National Academy of Sciences and the National Academy of Medicine (US Academies) [2].

This document's conclusions, however, were surprising since it recommended the use of germline gene editing in human beings, in certain specific circumstances, even though the following international law on the matter opposed such an alternative:

(1) The United Nations Educational, Scientific and Cultural Organization's (UNESCO) *Universal Declaration on the Human Genome and Human Rights* (1997) which indicates in Article 24 that germline interventions could be considered as a practice that would be "contrary to human dignity".

(2) The Council of Europe Convention on Human Rights and Biomedicine (1997), which states in Article 13 regarding "interventions on the human genome" that "[a]n intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants".

Amongst a number of concerns, one of the reasons why germline interventions are rejected in these legal texts is because they express a eugenic development. This describes selection strategies or decisions aimed at affecting, in ways which are considered to be positive, the genetic heritage of a child, a community or humanity in general [4]. Indeed, it is very likely that unacceptable discrimination may result from such selection strategies which may undermine the equality in worth and value of all human beings which is the very basis of civilised society.[1]

At this stage, however, it is important to examine which gene editing procedures could be considered as eugenic. Indeed, there may be distinct categories dependent upon the development stages at which the editing is being considered.

1 It should be noted that a decision not to have a certain kind of child may also be based on other factors, such as a genuine psychological, financial and material inability by some parents to cope with a very seriously disabled child. Such a decision would not then be eugenic in nature.

Gene editing of very early embryos

If, for example, gene editing takes place on a very early human embryo (such as a two-cell embryo), a number of ethical challenges arise. Indeed, it would be difficult to know whether any significant genetic change would bring about a completely new individual or whether the original embryonic individual continues to exist and is simply modified [5].

In a way, this philosophical conundrum is not new and comes in many forms. It is similar to the one mentioned by the Greek historian, Plutarch (c. 46–120), who questions, in a thought experiment, whether a ship which is restored by replacing every one of its wooden parts remains the same ship.

From an ethical perspective, if the genetic modification does not give rise to any significant change in the already existing embryo, it would no doubt be seen as similar to somatic gene therapy in which the original individual remains.

However, if the gene-editing procedure substantially modifies the genome of a very early embryo, more questions relating to the continued existence of the original embryonic individual could be asked. Genetic modification may then actually end the life of the original embryo (a form of death) while creating another. This would then have a clear eugenic element since it would mean preferring one new being over another based on the quality of his or her genome.

Gene editing of sperm, eggs and during fertilisation

On the other hand, if a genetic modification takes place either on the sperm and egg cells before they are used or during fertilisation, such as in the formation of a one-cell embryo, a new individual, who would not otherwise have existed, is being brought into being. This would happen because any change (no matter how small) of any of the variables in bringing an individual into existence would result in a very different individual existing in time [6].

This again has a clear eugenic element since a new individual is being brought into existence in preference to another (who may for example have had a genetic disorder). What is being proposed, therefore, is not a form of therapy since no existing person is being treated for a disorder. Instead, it is making sure that only certain persons are brought into existence based on the quality of their genomes.

Discussion

Of course, it is possible to ask what is ethically wrong in deciding to make sure that only healthy and not disabled children are brought into existence. Why not make sure that children who will have a short and difficult life of suffering are not brought into existence? In response to these questions, it is important to recognise that it is difficult to see how parents can decide not to have certain kinds of children without making a value judgement that some children are less desirable. It follows, that when parents make a decision that only a certain kind of child should be brought into existence, based solely on genetics factors, this can only mean making a eugenic choice and preferring one child over another. In other words, this decision contradicts the important principle that the lives of all human beings have the same worth and value, regardless of their state of health [7].

Indeed, if *"all human beings are born free and equal in dignity"*, as stipulated in Article 1 of the UN's Universal Declaration of Human Rights, how can a choice between two supposedly equal future persons ever be made?

To be sure, it is possible to argue, as does the 2017 US Academies report, that "unconditional love for a disabled child once born and respect for all people who are born with or who develop disabilities are not incompatible with intervening to avert disease and disability prior to birth or conception" [2, p. 97].

But the report does not explain how or why any deliberate discrimination can be seen as acceptable before birth while suddenly becoming unacceptable at birth. Moreover, if parents do decide to avoid having a child affected by a serious genetic disorder, based solely on genetics factors, the indirect message being given to persons, who have already been born with the same disorder, is that they should also not have existed.[2] This is clearly discriminatory and would undermine the inherent equality of all human persons in society.

Naturally, it is impossible not to have a lot of sympathy towards parents who have children affected by severe disability and suffering. But, if one asks these parents, it is always the disorder and not the very existence of the child with the disorder that has been the cause of so much heartache. Moreover, none of the parents would say that they would have preferred to exchange their child for another, healthier one.

In summary, if intentional germline selection is accepted (such as with gene editing), this would in the words of a 2015 UNESCO Bioethics Committee report, *"jeopardize the inherent and therefore equal dignity of all human beings and renew eugenics, disguised as the fulfilment of the wish for a better, improved life"* [8].

It was in order to address such a danger that Article 3 of the EU Charter of Fundamental Rights (2000) was drafted which state that: "In the fields of medicine and biology … the prohibition of eugenic practices, in par-

2 For clear evidence of the feeling of offence being taken by persons with disability in such a situation, it is useful to refer to the disability witnesses in the prominent French court case of Nicolas Perruche Public Hearings of the French Senate on the 18th of December 2001 relating to the jurisprudence of the "Perruche" case.

ticular those aiming at the selection of persons" must be respected.

Note: The views expressed in this article are those of the author and do not necessarily reflect the positions of the professional organisations with which he is affiliated.

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