

Human Genome Editing
Human Dignity in an Era of Genetic Nobility

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Abstract

Genetic engineering brought to man what, until now, was only given to destiny, chance or to God and, in any case, all of them purely determined by *unhuman* purposes. The determination of the identity and historicity of man, unique to each being, can be engineered. Man's *creator* can be, now, a *peer*, that takes into his hands, especially at the level of the biotechnology promises of human *enhancement*, the genetic programming of others, altering their genetic heritage and, at the extreme limit, their own identity leading to a manipulative process of their future by altering their genomic legacy. The possibilities of the *breeding* of the species is seductive, and even considering the *good intentions* argument, truth is that, immediately, historical lessons of improvement of the species come to mind. Although we evidently do not compare them, the atrocities of World War II and the eugenic justification of the *hygienization* of the species ended in a genocide. We are confronted to a new evolution road and decisions need to be taken in a broad consensus. Considering the consequences, either in the individuals and in society in general, singular options does not fulfil a responsible compromise in the conflicting rights. We stand before two extreme limits. In one hand, the (moral) *duty* to use genetic engineering and the multiple scientific solutions to give the *best* opportunities to our children, improving their characteristics and help them to adapt. *Natural selection* can be seen in a deficit considering the overwhelming and escalating mutations we are facing in many levels of our life. However, at the very opposite, the absolute refusal to use the biotechnologies and let nature take its course. In between we can have all shades of *grey solutions*. An imperative ethical and legal debate imposes itself, in which human dignity will, in our view, be the ultimate criteria of legitimacy because at the end the main question we need to be prepared is how establish the difference between creating humans or creating *pedigree* things. It is at this historical moment we stand for.

Keywords: Genetic Engineering; Human Enhancement; Human Dignity; Eugenics; Bioethics; Biolaw.

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Introduction

Displaying moral character is essential in an era where biotechnology is part of our life and it can influence the *creation* of the being of our children. This is a new challenge, like no other humankind as ever faced, and, what we have to compromise, is the content of the principles governing genetic engineering, especially at the level of human reproduction and to enhance the natural characteristics of the future generations.

Modern biotechnology can generate and provide a true human “*quality control*” through the composition of the genome, selecting genes *à la carte*. We can now compose and take an active part into human evolution. The *creature* is in jeopardy of being a *mere* object and a new form of *commodities* can arise, generating the devaluation and disqualification of the human being.

Such ethical and legal questions, and the frontier between reproduction or *breeding* of a (*pedigree*) thing, in a Kantian postulate, is what is to be establish in CRISPR/Cas9¹ (or similar technologies), mainly when used to genetic enhance natural characteristics of the future generations reshaping their genetic heritage. A regulation is needed in this universal problem that does not compromise with *mere* local positions and asymmetric solutions that can generate inequities between and within societies.

Our question is if human dignity can establish the universalist ethical principle around homogeneous consensus in this new era of *genetics à la carte*.

Playing with destiny

The President's Commission for the Study of Ethical Problems in Medicine, Biomedical and Behavioural Research, recognized that “*genes are perhaps the most tangible correlates of who a person is as an individual and as a member of a family, race, and species*” (p. 10). The CRISPR/Cas9 (or similar technologies) is an important tool to genetic engineering, including human subjects, and it placed into our hands human evolution, either in therapy use or, even, as an enhancement tool².

The technology is beyond attractive and Mr. He Jiankui didn't resisted it. In fact, the palpable possibilities and the fascination of these technologies made Mr. He open a door that, for now at least, should have been closed. He created the first gene-edited babies in China claiming that he edited the twins' DNA, making them resistant to HIV. Many, around the world, claimed that the experience was unethical, and exposed embryos to unnecessary risks. Mr. Jiankui was furiously criticized for conducting an experience with no purpose at all except as a mere narcissist practice, apparently placing himself in the podium to a “new race to the moon” where, hopefully, he is alone.

¹ “Clustered regulatory-interspaced short palindromic repeats”.

² We are considering the definition of the President's Council on Bioethics. We use “therapy” “(...) as in common understanding, is the use of biotechnical power to treat individuals with known diseases, disabilities, or impairments, in an attempt to restore them to a normal state of health and fitness. “Enhancement,” by contrast, is the directed use of biotechnical power to alter, by direct intervention, not disease processes but the “normal” workings of the human body and psyche, to augment or improve their native capacities and performances” (The President's Council on Bioethics, 2003).

Even research in human embryos is problematic, although, as we can conclude from the 2015 International Summit co-hosted by the US National Academy of Sciences and US National Academy of Medicine, the UK Royal Society, and the Chinese Academy of Sciences were against a completely ban on GGE (Gyngell, Douglas, & Savulescu, 2017, p. 499) although, the geneticist George Church, in a recent interview to Science, stated that “(...) *there’s a moratorium on germline editing (...), but a moratorium is not a permanent ban forever*”.

We can establish a common ground of ethical concerns surrounding GGE and, according to Professor Savulescu we can identify two main principles to genome research:

“1. Risk should be reasonable (Savulescu & Hope, The Ethics of Research). This includes that risks are minimized and that there are proportionate benefits. There would have been less expected harm if embryos with lethal disorders were used. Any child produced would stand to derive a very significant benefit: having their life saved. Lulu and Nana derive no direct benefit: HIV can be prevented in numerous ways, including by protected sexual intercourse. Yet they were exposed to significant risk of off target mutations and cancer. The benefits to them are not proportionate to the risk.

2. Consent should be obtained. Clearly embryos cannot consent. Research on incompetent participants can be ethical if it is minimal risk or the benefits are proportional to the risks. This would only be the case if the embryo had a lethal disorder, and not when the embryo and future child only stands to be harmed with no direct benefit” (Savulescu, 2018).

The power of today in tomorrow’s generation, in the determinism of their life projects, collides with their freedom and self-determination, with no way to reverse the process we need to compromise in a balanced composition of all interests in conflict. The *vexatio* question is in what grounds we should build a fruitfully debate to achieve (a minimal) homogenous ethical recommendations and an internationally recognized legal framework to legitimate, or not, or in what density, the CRISPR technologies either to therapy or even to enhance our genetic heritage in, *in extremis*, a consumer-based relationship.

Breeding Humans

Respect for private life demands that all humans are free to establish their life project, assuming their identity, integrity and autonomy, without any form of manipulation, including their genetic heritage as a key element of their identity. However, on the other side, the reproductive autonomy claims for the ambition to guarantee the *better* characteristics science can provide our offspring. Asked in a simple way “*what father or mother does not dream of a good life for his or her child? What parents would not wish to enhance the life of their children, to make them better people, to help them live better lives? Such wishes and intentions guide much of what all parents do for and to their children. To help our children on their way and to make them strong in body and in mind, we feed and clothe them, see that they get rest, fresh air, and exercise, and take great pains regarding their education. Beyond ordinary schooling, we give them swimming and piano lessons, enroll them in Scouts or Little League, and help them acquire a variety of skills-artistic, intellectual, and social. In addition,*

we try to develop their character, educate their tastes and sensibilities, and nurture their spiritual growth. In all of these efforts we are guided, whether consciously or not, by some notion or other of what it means to improve our children, of what it means to make them better.” (The President's Council on Bioethics, 2003).

To illustrate the conflicting positions, “*essentially, the more two options are equally attractive/ unattractive, the more time we spend agonizing over the decision. Ethical hard case, such as whether or not to provide life sustaining treatment to an extremely unwell child, might be difficult precisely because we don’t know how to choose between different outcomes*” (Brown, 2018). The same paradox presents itself in GGE.

In any case, and no matter the option we make, the responsibility becomes ours and, in any case, there are no neutral positions, but it must not stop us. The concern is universal and does not compromise with local and asymmetric positions; ethical principles should be built around universal consensus. For us this value is human dignity.

Despite the multi-layered origins of human dignity the UDHR gave it a universal dimension and we can conclude, following Carozza that “*dignity serves both to indicate the foundation of rights in the Universal Declaration (the status of equal and inherent human worth) and also to highlight some of the normative implications of that status*” (2013, p. 346). It serves as a bond today in the same way it served when the UDHR was being drafted. It is told that when discussing the content of the UDHR “*(...) the participants were able to agree on what they were against, but not on why they were against these violations. Human dignity, so the story goes, was inserted as a placeholder when those drafting the Declaration failed to agree on any single foundation*” (McCrudden, 2013, p. 2).

This multi-layered concept has ancestries in different backgrounds (Dupré, 2013, p. 113). As an exemplificative exercise we can relate human dignity to “*the idea of human beings as imago Dei*” (Dellavalle, 2013, p. 435) and we have palpable contributions of the Roman Catholic Church for the moral conception of human dignity. For instance, Pope Leo’s XIII encyclical on capital and labour establishes, in the relation between the owner and employer: “*(...) not to look upon their work people as their bondsmen, but to respect in every man his dignity as a person ennobled by Christian character*” (Rerum Novarum, 1891).

We can also consider, amongst others, the important role of Pope John XXIII. In his encyclical *Pacem in Terris*, from 1963, establishing Universal Peace in Truth, Justice, Charity, and Liberty, reinforces the *Imago Dei*, “*God created man "in His own image and likeness”, and reinforces man’s rights “We must speak of man's rights. Man has the right to live. He has the right to bodily integrity and to the means necessary for the proper development of life (...)*” (Pacem in Terris, 1963). The Second Vatican Council *Gaudium et Spes* and *Dignitatis Humanae* influenced the doctrine of the Catholic Church maintaining the heritage of that religious influence in the development of the concept.

In a philosophical view we cannot erase “*Kant’s contribution to our current understanding of human dignity (...), as he helped to articulate the notion in nontheological language*” (Pullman, 2014, p. 21).

Despite the multi-origins that human dignity has associated it gained a statute of “*(...) universal truth that, to the UDHR, was (is) an essential value which served as a foundation for the legitimacy of human rights*” (Nichols, 2013). It was then, it is now.

Is Human Dignity a mere slogan?

Can we say human dignity is a valid argument? Or just a mere rhetorical statement? Carozza points out that “*(...) the answer undoubtedly lies in dignity’s capacity to evoke an ideal that could have a broad and enduring application and appeal (...)*” (2013, p. 348). Since the preamble of the UDHR, that states the human “*recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world*” (Caulfield & Chapman, 2005), there are numerous examples of documents that evoke human dignity as a background and a limit to deal with controversial science issues. For instance, the Universal Declaration on the Human Genome and Human Rights, the 2005 UNESCO Declaration on Bioethics and Human Rights, the Oviedo Convention, the Helsinki Declaration.

But, some, didn’t inserted it. The main example is the ECHR. Following Jean-Paul Costa, Buyse concludes that the absence of any mention was “*(t)o make sure that the ideals of the Universal Declaration would not be lost in space, or, more specifically, in the trenches of the Cold War, the European drafters created practical instruments such as a human rights court and binding obligations for states by way of a treaty. Pragmatics rather than dreams*” (Buyse, 2016). However, later Protocol No. 13 on the abolition of the death penalty, ended up mentioning the term “dignity” and, since then, other documents followed.

However, we can conclude that “human dignity” is a judicial argument. As Jean-Paul Costa identifies the Tyrer v. United Kingdom, from 1978, as the pioneer judgement (2013, p. 395), since the ECtHR addressed the human dignity directly and has done it in different decisions since then.

In Europe, the human dignity value gained a new strength and “*dignity also features prominently in the European Union Charter of Fundamental Rights*” (McCrudden, 2008, pp. 671-672). The principle “*(...) in the EU Charter dignity comes before life, and this arguably going to change the understanding and protection of the right to life, with the consequence that the concept of life in dignity might complement, and perhaps challenge, the principle of sanctity of life in ways that have yet to be explored and discussed*” (Dupré, 2013, p. 115).

Considering the compromise to human dignity that all of the documents make, directly or not, we can say that the value is a widely shared and serves as the foundation for our understanding of human rights. For us, essential is, in the first place, a debate. Not only at a scientific level but a broader one including all stakeholders. And, in the words of Adorno, “*(...) the reality is that it reflects a real concern about the need to ensure respect for the inherent value of every human being*

and of humanity” (2009, p. 93) so, because of that, the solution does not compromise with authority positions but a democratic decision. Besides the limits that needs to be established in genetic engineering, what we grant today is to be our responsibility tomorrow, the responsibility to our children, the responsibility of their genetic programmes and responsibility to the society we are building for them and to them.

So we ask. Why human dignity? and Why now? Our conceptions of the role of human dignity is a structural one. A value that points an evolutionary path to new biotechnological solutions. We can all agree that “(...) *there is a danger that we lose sight of the simple virtue of doing the right thing*” (Brownsword, 2013, p. 358) so not losing the sight of dignity imposes obligations upon us. Biomedical regulations refer “(...) *to a certain quality or characteristics that links them to the human species*” (Beers, Corrias, & Werner, 2014, p. 11) and, at the end, the heritage of human dignity reapers with a present and renewed importance.

As stated by the French Philosopher Maritain “*no declaration of the rights of man can ever be exhaustive and final. It must always be expressed in terms of the state of the moral conscience and of civilization at any given moment of history*” (1947). This evolution of the human rights and the new challenges posed has, at the end, human dignity as a value to fulfil.

The genetic programming of the next generations is assuming itself as a new form of *generational* responsibility. These concepts “(...) *have been remolded and reconstructed to fit the purposes and values of biomedical regulation*” (Beers, Corrias, & Werner, 2014, p. 9). The foundation is, in our view, in human dignity as a standard for moral status and, “*to have moral status is to be an object of moral concern, and moral agents owe duties and obligations to an entity with moral status*” (Holland, 2017, p. 9).

Considering that foundation given by human dignity the concept gives an understanding and a path to the needed discussion surrounding human genetic engineering and “*ultimately, without such principle, we have no basis on which to sustain the ongoing conversation that defines and articulates our common humanity*” (Pullman, 2014, p. 25).

In another perspective, biotechnology has a direct influence in our private lives but also in the community and the society we are building. Since the “(...) *use of biotechnical powers to pursue "improvements" or "perfections," whether of body, mind, performance, or sense of well-being, is at once both the most seductive and the most disquieting temptation. It reflects humankind's deep dissatisfaction with natural limits and its ardent desire to overcome them*” (The President's Council on Bioethics, 2003), one’s genetic inheritance, personal integrity and identity are rights that we need to maintain and assure. Albeit the seductive laboratorial *breeding* of the specie, or concrete specimen, which the human enhancement promises in a palpable creation of *genetic supremacy*, takes the issue to a frontier debate, of positive eugenics and human nature itself.

Human dignity is the foundation and the ultimate goal to be sought in all circumstances. Genetic engineering can be a new form of control and manipulation so is essential a balanced composition of the conflicting fundamental rights. What we compromise today in new biomedical options will reshape not only the future

generations but also society and will transform humankind leading it into a new evolutionary path for the *homo sapiens sapiens*. As Marco says “*finding out when such changes mitigate (or fully undermine) responsibility for some actions can help to guide how (or whether) we hold responsible those who have undergone such changes as the result of treatment (...). It may also help to illuminate some of the moral factors involved in deciding whether to perform certain types of treatments*” (Marco, 2018).

Considering He’s experiment the real problem, was that the egoist decision taken by the Chinese scientist is to be plural and, at the end, belongs to all of us (Hurlbut, 2019) since it means to determine the new path of human evolution.

Human dignity constitutes the portal through which the egalitarian and universalist content of moral is imported into law and legitimates its solutions, the minimal ethical is to be determined. In the actual moment of science, the choice for the gene enhancement has the possibility to improve each person’s characteristics to better adapt, ensuring a better and improved quality of life, enhancing the opportunities that may reasonably aspire. CRISPR solutions not having a patient but, also, a consumer as is, the principle of welfare is based in a life-saving purpose or more than that?

The evolution of man is not, now, only a natural one. We can interfere, with our genomic heritage and program our offspring to something more or less different that their heritage would provide. As we said, this possibility, and the position we make towards it, will determine the *new* substance of human rights but the value human dignity must stay untouchable.

In any case, there are no neutral decisions, and we will have to live with the consequences and, most importantly, in a non-alterity relation, make our children and their descendants live with the consequences of our programming choices.

Conclusions

The many understandings human dignity can have, in a more or less liberal position, with a religious or secular connotation, with a concrete philosophical interpretation that each and every one of us might have about it is just a sign of pluralism. The (apparent) weakness of dignity is its most strength.

The divergent understandings are a point of convergence. A value where each one, despite our differences, can feel, at some point, related to and, for that, related to the one that have a different understanding about it.

Creating the basis of a fertile plural and meaningful debate, building bridges amongst our differences, opened to all with increased self-awareness. “*(D)eeply contested problems of where human rights came from, and what their foundations are, in favour of reaching a consensus about what specific fundamental rights could find universal acceptance*” (McCrudden, 2013, p. 16). Quoting Réaume we can say “*dignity is bound up with our attribution of inherent worth to human beings. To ascribe dignity to human beings as a moral matter is to treat human beings as creatures of intrinsic, incomparable, and indelible worth, simply as human beings*” (2013, p. 540).

In the position of Ronald Dworkin, that we share, all humans share a single status and we all owe equal concern and respect (Dworkin, 1977) and “*human dignity is one of*

the most pervasive and fundamental ideas in the entire corpus of international human rights law. From 1948 to the present, the formal instruments of international human rights make consistent reference to dignity” (Carozza, Human Dignity, 2013, p. 345).

After seven million years of Human evolution the new stage in this path is now, the least we can say, different but what we need to compromise is to maintain human dignity as the value to fulfil in any circumstance.

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