

Genome editing, Justice and Autonomy

Maurizio Balistreri

(Department of Philosophy and Educational Science;
University of Turin)

Genome Editing, Social Justice and Equity

Genome editing as a 'class' project?

Genome editing as an enhancement rat race?

Genome editing as a gender project?

Justice and Genome Editing Technologies

Genetic correction and enhancement procedures could have a high or even prohibitive cost: maybe only the best-off people will be able to afford them.

A CNBC SPECIAL REPORT  Find out here

SPONSORED BY

اقتصاد
ADNOC



HEALTHY RETURNS



CNBC

INVESTING IN
HEALTH CARE
INNOVATION

**NEW YORK
CITY**
MARCH 28, 2018



A US drugmaker offers to cure rare blindness for \$850,000

- Spark Therapeutics' Luxturna will cost \$850,000 for a one-time treatment.
- The gene therapy treats a rare, inherited retinal disease that can lead to blindness.
- Spark also unveiled a set of payment and access programs, including tying payments to how well the therapy works and exploring payment by installment.
- These programs could serve as a model as more one-time treatments come to market.

Meg Tirrell | [@megtirrell](#)

Published 8:30 AM ET Wed, 3 Jan 2018 | Updated 11:52 AM ET Wed, 3 Jan 2018



What Should Gene Therapy Cost?

Posted October 26, 2017 by [Ricki Lewis, PhD](#) in [Uncategorized](#)



112

By the time that the FDA's advisory committee gave a near-instantaneous and unanimous **thumbs-up** for gene therapy to treat a form of hereditary blindness on October 12, tears were freely flowing. Fittingly, it was **World Sight Day**.

The new drug, Luxturna, is a one-time injection of a working gene into the eye to treat ***RPE65* mutation-associated retinal dystrophy**. When the final stamp of approval arrives in January, Luxturna will be the first gene therapy approved in the US for a single-gene disease.

Email

☐ I have read and agree to the [terms of use](#), [Privacy Policy](#), and [Data Policy](#).
Send me the PLOS ONE newsletter

Sign up

Popular



Tag Cloud

23andMe AD

Justice and Genome Editing Technologies

Moreover, we could even imagine 'universal' access to genome editing. The point is that the last generation could always have more advantages than the previous ones, because it could have access to better and original interventions.

Robert Sparrow

Enhancement and Obsolescence: Avoiding an “Enhanced Rat Race”

ABSTRACT. A claim about continuing technological progress plays an essential, if unacknowledged, role in the philosophical literature on “human enhancement.” I argue that—should it eventuate—continuous improvement in enhancement technologies may prove more bane than benefit. A rapid increase in the power of available enhancements would mean that each cohort of enhanced individuals will find itself in danger of being outcompeted by the next in competition for important social goods—a situation I characterize as an “enhanced rat race.” Rather than risk the chance of being rendered technologically and socially obsolete by the time one is in one’s early 20s, it may be rational to prefer that a wide range of enhancements that would generate positional disadvantages that

Risks for reproductive freedom

Then, we must also be aware that introducing new reproductive technologies may negatively affect our 'reproductive freedom'. There is the risk that genome editing in the embryo (in both therapeutic and enhancing versions) becomes mandatory for people who wish to have a baby.

A close-up photograph of a white ceramic spoon. A single green and black capsule is balanced on the spoon's bowl. The background is a soft, out-of-focus light blue.

INTRUSION

KEN MACLEOD

Intrusion by Ken Macleod

Hope won't take "the fix", a pill that cures genetic disease, and corrects all the errors in a foetus's genome. She's refused once, but pressure to comply is mounting and she won't get away with it again. She could easily claim faith group exemption, but she won't. She won't give reasons; she insists it's simply her decision.

About reproductive freedom

New eugenics start from the idea that the parents' freedom of choice constitutes the best antidote against the danger of coercive state policies.

Reproduction at the age of genome editing

However, with the arrival of genome editing, correcting the unborn child's DNA may seem the most reasonable and moral thing for a 'future' parent to do. Indeed, correcting the genetic code could be relatively simple: and the result would of course be that the embryo would come into the world without genetic anomalies.

Reproduction at the age of genome editing

If we assume that upbringing and genetic changes are analogous processes, why should a 'liberal' state consider upbringing obligatory but leave the gene therapies or enhancement completely to their parents?

Reproduction at the age of genome editing

Nevertheless, if germline genome editing became (legally) binding, women might be 'forced' to reproduce with ART and take responsibility and care about the genome of 'future generations'.

Reproduction at the age of genome editing

Indeed, if the embryo were produced in vitro, diagnostic and later therapeutic intervention could be practised at once, at the moment of conception or immediately after. But if the embryo were produced sexually, genetic editing could only be performed in an advanced phase of embryo development, because many days could go by before the pregnancy is discovered by the woman.

Reproduction at the age of genome editing

If fertilisation occurred with assisted reproduction, genome editing may be practised on the zygote or on blastomeres. In contrast, if reproduction goes through sex, the germline genome editing would have to be practised on an multicell embryo: the risk of error would, then, be greater, as would the probability that some cells of the embryo do not receive the desired modification.

Genome editing as Gender Project?

Given that if genome editing becomes feasible, it will be a “gender project”, there is the risk that women who do not agree to let their embryo undergo genome editing intervention are considered morally irresponsible.

Genome editing as Gender Project?

It is not necessary for genome editing to become legally binding; women could be penalized and discriminated against simply on a moral level.

Genome editing as Gender Project?

Today, women who choose to have a child are often criticised if at the moment of conception, pregnancy and birth they also think of their own interests. Many people expect the pregnant woman to undergo invasive interventions to allow the condition of the embryo's health to be monitored regularly.

Genome editing as Gender Project?

Further, it is often maintained that birth should always occur in hospital and women who choose labour and birth at home or in a maternity home put their own interests before the unborn child's: so they are bad mothers.

Homebirth and the Future Child

Lachlan de Crespigny, Julian Savulescu

ABSTRACT

Debate around homebirth typically focuses on the risk of maternal and perinatal mortality and morbidity – the primary focus is on deaths. There is little discussion on the risk of long-term disability to the future child. We argue that maternal and perinatal mortality are truly tragic outcomes, but focusing disproportionately on them overshadows the importance of harm to a future child

crime, both against the unborn child and against society; and if the principle of non-maleficence is taken seriously, the State ought to have a duty to prevent such harm. *charge*, as far as possible, on the basis of the evidence.

On 4 September 2012, a UK woman gave birth at home that a mother died within 24 hours of giving birth at home.² According to reports, the woman had previously delivered twins by emergency caesarean section.

Genome editing as Gender Project?

Widespread, vocal disapproval of public breastfeeding is well documented, but women also face pressure when they decide not to breastfeed: “For many – as Fiona Wolland and Lindsey Porter argue – the message they receive is clear: mothers who do not breastfeed ought to have a darned good reason not to; bottlefeeding by choice is a failure of maternal duty” (p. 515).

PAPER

Breastfeeding and defeasible duties to benefit

Fiona Woollard, Lindsey Porter

Department of Philosophy,
University of Southampton,
Southampton, UK

Correspondence to

Fiona Woollard, Department
of Philosophy, University of
Southampton, Southampton,
UK; f.woollard@soton.ac.uk

Received: 26 July 2016
Accepted: 6 December 2016
Published online: 6 January 2017
© Springer Science+Business Media
B.V. 2017

ABSTRACT

For many women experiencing motherhood for the first time, the message they receive is clear: mothers who do not breastfeed ought to have good reasons not to; bottle feeding by choice is a failure of maternal duty. We argue that this pressure to breastfeed arises in part from two misconceptions about maternal duty: confusion about the scope of the duty to benefit and conflation between moral reasons and duties. While mothers have a general duty to benefit, we argue that this does not imply a duty to carry out any particular beneficent act. Therefore, the expectation that mothers should breastfeed unless they have sufficient countervailing reasons not to is morally unwarranted. Recognising the difference between reasons and duties can allow us to discuss the benefits of breastfeeding and the importance of supporting mothers who wish to breastfeed without subjecting mothers who bottle feed to guilt, blame and failure.

practices from midwives and other health professionals,¹ to the detriment of thorough neonatal care support. Even if one thought that pressure to breastfeed increased rates of breastfeeding and that this led to a net health gain for mothers and infants, in general, these negative consequences for formula-feeding women and their neonates would give reason to search for alternative ways of improving breastfeeding rates. However, there is no reason to think that pressure to breastfeed can be counterproductive in terms of increasing breastfeeding rates. Lee and Furedi report that “women can come to distrust professionals, and become sceptical about the value of professional knowledge and advice”.¹

We argue that this pressure arises in part from two misconceptions about maternal duty. First, confusion about the scope of the maternal duty to benefit and second, conflation between

Genome editing as Gender Project?

Also in this case the pressure arises in part from a misconception about maternal duty: “the assumption arises from the fairly uncontroversial belief that mothers have a general beneficent duty towards their offspring and that if a given act benefits their children, they always have a duty to perform it” (p. 516).

Genome editing as Gender Project?

Why should we think that this attitude to women will change at the very moment when we use such technologies as germline genome editing? We cannot write off this problem as something not so important: in fact, secular and religious bioethics largely converge on women's moral responsibility.

Genome editing as Gender Project?

Mothers clearly have a general duty to benefit their offspring: but this does not imply a duty to carry out each particular beneficial act. “Mothers do not have a moral duty to carry out each and every act that would benefit their baby” (p. 515).

Genome editing as Gender Project?

An assessment that does not take into consideration the interests of everyone concerned is only partial, and not entirely rational. The future child's best interests are important, but the mother's are just as important and worthy of attention.

Genome editing as Gender Project?

I agree that genome editing could be used to solve issues related to health care, resulting, by and large, in a substantial improvement of public life. But women should not be required to justify their reproduction decision and be subject to blame if they do not have a baby by assisted reproduction.

Genome editing as Gender Project?

Reproductive risks have always been a part of woman's life: assisted reproduction would add new and important risks to motherhood.

Genome editing as Gender Project?

As Frida Simonstein explains, “IVF requires the use of drugs to stimulate the production of multiple ova, following which the ova are removed from the woman’s body, fertilized and inserted into her uterus”. (p. 5). “Would it be fair – Simonstein wonders – to add the pain and the risks involved in IVF to women’s challenging reproductive tasks?”



[Science and Engineering Ethics](#)

pp 1–10 | [Cite as](#)

Gene Editing, Enhancing and Women's Role

Authors

[Authors and affiliations](#)

Frida Simonstein 

Original Paper

First Online: 02 February 2017

2k

Downloads

Abstract

A recent article on the front page of The Independent (September 18, 2015) reported that the genetic ‘manipulation’ of IVF embryos is to start in Britain, using a new revolutionary gene-

The future of genome editing

Imagine that you can take a pill that cures genetic disease, and corrects all the errors in a foetus's genome. Or imagine that you can have in vitro gametes and use an artificial womb: in this case what are the woman's moral responsibilities?

Conclusion

The conclusion is that we must think about the responsibilities we have towards future generations and how fair it is to balance their interests with our own. Demanding that once pregnancy has been chosen, the woman sacrifice all her interests and well-being for the unborn child's well-being is unfair.