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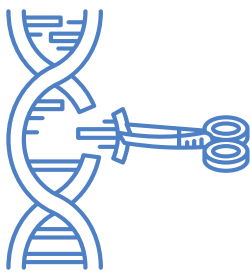
# A Potential Approach to Ethical Embryonic Editing: A Proposed Philosophical Framework

Hallie Young

In 2018, Chinese scientist He Jiankui blurred the lines between medical fiction and reality by revealing twin babies born from genetically modified embryos[1]. The unprecedented announcement provoked debates among bioethicists concerning the moral implications of irrevocably editing the human genome. While contemporary consensus regards human germline editing morally repugnant, advancements[2] in genetic technology have underscored the need for reopened discussions of human genetic modifications, especially before-birth, germline-affecting modification (i.e., Embryonic Genetic Editing or EGE). EGE is a process that cuts, replaces, or otherwise alters specific DNA sequences in early-stage embryos, resulting in changes that can be inherited by the embryo's offspring. EGE's invaluable therapeutic potential may be ethically realized given a proper framework. Under such a framework, EGE will answer common objections to justify its acceptance as an ethical and effective practice.

## Framework for Ethical EGE

Based on the concepts of Autonomy (1) and Benefit (2), I propose that, for an EGE modification to be a morally permissible[3] practice, it must:



- (1) be conditional on obtaining prior and informed consent from (when applicable) the egg provider, gestational carrier, and intended parents, and
- (2) carry a reasonable expectation for improved Quality of Life (QOL) for the edited party. Genetic modifications cannot be morally permissible if they carry merely an equivalent or diminished QOL.

The premises of the Autonomy-Benefit Concept Framework (ABC) are constructed to preclude concerns typically surrounding EGE; the Condition of Autonomy (1) avoids appropriating genetic material or body without prior approval and ensures that intended parents are not misled into believing their child will receive unmodified genetic material. The Condition of Benefit (2) prevents trivial modifications (in cases of estimated equivalent QOL compared to no modification outcomes) or modifications expected to disadvantage the child (in cases of diminished QOL).

ABC does not declare what qualifies as a necessarily improved or diminished QOL nor does it claim who should or could make such decisions. This framework is an argument of ideal moral theory and a tool to prove EGE's permissibility.

### Objection of Consent

Humans born from edited embryos are unable to consent to their EGE modifications. EGE critics cite embryonic nonconsent as proof of EGE's inherent immorality, but this objection ignores the certainty that embryos do not consent to any procreative decision. Parents inevitably make autonomous choices to which their future children cannot feasibly consent (e.g., with whom to procreate, at what age to reproduce, what food to consume during gestation, etc). EGE embryos hold at least as much power over their birth as non-EGE embryos.

ABC's treatment of future children arguably promises more permissibility than non-EGE procreative decisions because ABC considers a child's best interests. Intending another's best interest when consent becomes impossible is generally permissible. Suppose the following:



*There is a comatose man and a button. The man suffers a condition that floods every moment of his life with acute agony. However, pressing the button will make this condition disappear and grant the man health. The man has no proxies, his preferences are unknown, and he cannot communicate in any way. His coma is unaffected by the button.*

Pressing the button entails acting without the man's consent, yet it is instinctually the more appealing choice. The button's expected benefits to the man's QOL justify interference, and leaving the man to endure preventable suffering feels immoral. The underlying principle, viz., one is justified to act in another's reasonable best interest when consent is unknown and unattainable, can be applied to EGE: It is justified to act in the reasonable best interest of an embryo's future QOL.

### Objection of Nature

The inherent existential character of editing another's genetic material elicits concerns about "playing God" (i.e., exercising unnatural control over humanity and human bodies). This fallacious appeal to nature is problematic. In addition to being vague about what constitutes too much control, it ignores the inherent unnaturalness inextricable to contemporary living. Parents commit many "unnatural" acts that affect their children's bodies (e.g., vitamin supplements, vaccinations, essential surgeries) with the expectation of increasing the child's QOL. It is hypocritical to renounce EGE while engaging or allowing other unnatural practices.

### Objection of Disparity

There exists concern that EGE will exacerbate health outcome inequalities between the privileged and disadvantaged. However, it is unreasonable to burden EGE alone with protecting medical justice. Inequitable treatment for the underprivileged exists in every societal sector and remains inseparable from modern life's exploitative character. Even if the rich are the only population that could afford (and thus undergo) EGE procedures, they are already the only population affording other health luxuries (e.g., expensive surgeries, personal trainers, nutritious food); inequality (and subsequent health disparity) will exist regardless of EGE.

While it is disquieting to envision a society where the historically powerful are engineered to superhuman perfection and the oppressed languish, such a future is unlikely under ABC. ABC's Condition of Benefit restricts the trivial modifications pervasive in dystopias of reckless alteration. Additionally, as privileged progenitors endow descendants with beneficially edited genes, those descendants will have less need for scarce health resources (e.g., donated organs, expensive medication, or ventilators) thus freeing more of those resources for the public. Furthermore, EGE gaining greater acceptance and genetic technologies advancing could reasonably make genetic modification more accessible to the underprivileged.



### Objection of Eugenics

Eugenics is a form of population control intended to create a community with specific “ideal”[4] traits. Historically, eugenics is imposed by a government/higher authority and pursued with tactics like forced sterilization, genocide, segregation, or (theoretically) genetic engineering. Advocates for the vulnerable and marginalized (e.g., disabled people, racial minorities, Queer individuals) express that editing to remove certain traits is a modern form of eugenics.

Concerns of marginalized community decrease are understandable; there is precedent for falling disabled populations following the introduction of reproductive interventions. For example, Denmark's Down Syndrome birth rate decreased dramatically after the introduction of prenatal genetic screening (PGS). Denmark mothers whose PGS detects chromosomal aberrations indicative of Down Syndrome terminate their pregnancy 95 percent of the time, and there is a reasonable expectation that rates of Down Syndrome-preventing modifications will be similar when EGE becomes a more practical treatment option[5]. Activists express that termination at the first sign of Down Syndrome (and similar discriminatory reproductive choices) communicates a rhetoric of disabled defectiveness which views a disabled life as tragic and not worth living. These sentiments are similar to eugenic calls to eradicate the “feeble-minded.”

While the distress of disabled communities is legitimate, it would be remiss to assume ABC-guided EGE modifications promote eugenics. A primary factor of eugenics' atrociousness is a complete lack of consent; authoritative states force eugenics on a population through paternalist practices designed to inhibit the autonomy of the subjugated. Inversely, ABC views consent[6] as a *necessary* condition for permissible modification—similar reasoning justifies why the Danish mothers' decisions to terminate Down Syndrome pregnancies is not eugenics because they made an individual, autonomous reproductive decision. Furthermore, EGE does not intend to steer a population towards imposed ideals; permissibility is based on what best benefits the child and that will vary for different children in different contexts. There is no “base human” pursued in EGE procedures, only expected increased QOL.

Under ABC, to be permissible, all modifications must be expected to increase a child's QOL. It follows that any child modified by EGE would be expectedly worse off had no EGE occurred. Promoting vague disability advocacy ideals/increasing the population of certain conditions without regard for the remediable suffering of the otherwise-modified who serve that goal would be using those otherwise-modified as mere means to achieve an end.

Those troubled by populations of individuals with Down Syndrome (or similar conditions) have no justification for exploiting the lives and suffering of others for social change. The burden of improvement is not incumbent upon suffering fetuses; those alive must create a world where the conditions warranting protection do not necessitate diminished QOL. It is the responsibility of the living, not the unborn, to accept, accommodate, or cure.

### Objection of Lineage

Unlike somatic genetic editing which only affects the individual undergoing the procedure, EGE modifications are heritable changes that may be carried on through descendants. The ramifications of modifying an entire germline can appear overwhelming, but further contemplation reveals that lineage editing is merely the modification of a collection of *individuals*. Thus, many objections levied against germline editing (e.g., future descendants cannot consent to modification)[7] find answers in previous individual-focused refutations.



Admittedly, ABC bears conceivable weakness when discussing *individually* evaluated QOL concerning hereditary outcomes due to the difficulty of estimating one modification's impact on an entire lineage. Nevertheless, similar weakness may be observed in any significant decision estimated across a wide duration; it is not the business of mortals to know all the consequences they effect. At the least, one can act in service of what they reasonably expect is another's best interest.

Generally, what is beneficial for a parent will benefit the child, even if only indirectly. A parent unburdened by suffering or expensive accommodation can invest more time, money, and energy in their child's well-being.



## Notes

[1] Greely H. T. (2019). CRISPR'd babies: human germline genome editing in the 'He Jiankui affair'. *Journal of law and the biosciences*, 6(1), 111–183. <https://doi.org/10.1093/jlb/lso10>

[2] Wilkinson E. UK regulator approves “groundbreaking” gene treatment for sickle cell and  $\beta$  thalassaemia *BMJ* 2023; 383 :p2706 [doi:10.1136/bmj.p2706](https://doi.org/10.1136/bmj.p2706)

[3] Permissibility is a necessary but not sufficient condition for moral obligation. Similarly, The potential for permissibility does not equate to permissibility (i.e., expected benefit from modification is a necessary but not sufficient condition for moral permissibility).

[4] Ideal based on subjective, prejudiced, and often racist philosophies.

[5] Lou S, Carstensen K, Petersen OB, et al. Termination of pregnancy following a prenatal diagnosis of Down syndrome: A qualitative study of the decision-making process of pregnant couples. *Acta Obstet Gynecol Scand*. 2018; 97: 1228-1236. <https://doi.org/10.1111/aogs.13386>

[6] While a child cannot consent to modifications, the OBJECTION OF CONSENT establishes that parents may act as proxies in their child's best interest.

[7] For a response to this example, see OBJECTION OF CONSENT and Condition of Benefit