

## Culture and context: Why the global discourse on heritable genome editing should be broadened from the South African perspective

Donrich Thaldar, Bonginkosi Shoji, Tamanda Kamwendo\*

**ABSTRACT:** The global discourse on heritable genome editing is dominated by Western perspectives. A broadening of this discourse is advocated. A South African perspective on heritable genome editing is provided, focusing on differences in culture and context, which illustrates the need for a governance approach to heritable genome editing that is distinctly less restrictive. This, it is argued, is because categorical claims about the morality of heritable genome editing that are routinely expressed as worthy of being aspects of the global governance framework lack a recognition of differences in culture and context between different countries, and hence constitute ethical imperialism.

**KEYWORDS:** Culture; enhancement; eugenics; non-Western; South Africa

**SOMMARIO:** 1. Introduction – 2. Culture: Diversity in morality and the law – 3. Context: The practical reality of momentous public health challenges – 4. Conclusion.

### 1. Introduction

Imagine that you are a pregnant woman in your first trimester. Imagine further that you live in a country that is in the grip of a deadly epidemic with no vaccine in sight. If you could use a minimally invasive medical procedure to ensure that your unborn child is immune against the disease, would you use it? You may ask: “But is it safe and effective?” Let’s assume the answer is yes, it is—would you decline the opportunity to give your child a life where they do not live in fear of a life-threatening illness? Now let’s consider a unique rider, namely that the procedure will not only make your unborn child immune against the disease, but likely also your unborn child’s progeny. Would the heritable nature of the immunity change your answer?

The Covid-19 crisis is a reminder of our biological vulnerability as humans. While large-scale infectious disease epidemics are exceptional in the developed world, this is unfortunately not true in the developing world. Many developing countries are dealing with ongoing infectious disease epidemics, like Tuberculosis (TB), that do not seem to abate. Heritable genome editing may in the future offer

---

\* Donrich Thaldar, Associate Professor, School of Law, University of KwaZulu-Natal, South Africa. Mail: [thaldar@ukzn.ac.za](mailto:thaldar@ukzn.ac.za). Bonginkosi Shoji, Postdoctoral Research Fellow, Institute for Practical Ethics, University of California San Diego, United States. Mail: [bshoji@ucsd.edu](mailto:bshoji@ucsd.edu); Honorary Research Fellow, University of KwaZulu-Natal, South Africa. Tamanda Kamwendo, Lecturer, Faculty of Law, University of the Free State, South Africa. Mail: [kamwendot@ufs.ac.za](mailto:kamwendot@ufs.ac.za). The article was subject to a double-blind peer review process.

mechanisms of mitigating the harms caused by seemingly insurmountable healthcare challenges – although genetic technologies are, at present, not ready for use in a clinical context due to the enduring risk of unintended effects. But, if these technical issues are overcome, would it not be ethical heresy to even suggest the possibility of using heritable genome editing? Prominent voices in the global discourse on heritable genome editing have suggested this is so. Numerous declarations and statements issued since 2012,<sup>1</sup> when a group of US scientists published the first paper on the novel genome editing technology CRISPR-Cas9,<sup>2</sup> have alluded to the same. These include statements by both the groups of scholars<sup>3</sup> and institutions like the World Health Organisation,<sup>4</sup> arguing for the need to establish global principles and rules for governing heritable genome editing—in some cases advocating a world-wide moratorium on heritable genome editing research.<sup>5</sup> In light of the global endeavour to establish global standards on heritable genome editing, it is necessary to consider such value-laden questions and explore the extent to which cultural diversity and social contexts may inform varying perspectives. That is what this article will do.

In this article, we suggest that there has been a dominance of Western perspectives in the current global discourse on heritable genome editing, that are informed by the Eurocentric lens through which the ethical issues raised by HGE are often viewed. We advocate a broadening of this discourse to be more inclusive of different ethical perspectives. In particular, we focus on South Africa, and suggest that given (i) South Africa's culturally-defined norms in the domains of both morality and law, and (ii) the practical reality of momentous public health challenges in South Africa, the country can—and should—adopt a permissive approach to heritable genome editing.

## 2. Culture: Diversity in morality and the law

In using the term “Eurocentric” we refer to Serequeberhan's definition of Eurocentrism, which is as follows: “Broadly speaking, Eurocentrism is a pervasive bias located in modernity's self-consciousness of itself. It is grounded at its core in the metaphysical belief [...] that European existence is qualitatively superior to other forms of human life”.<sup>6</sup> This commonly presents itself in the assumption that European norms and lived realities are universal. In the discussion below, we will illustrate how Eurocentrism

<sup>1</sup> M. JINEK, K. CHYLINSKI, I. FONFARA, M. HAUER, J.A. DOUDNA, E. CHARPENTIER, *A Programmable Dual-RNA-Guided DNA Endonuclease in Adaptive Bacterial Immunity*, in *Science*, 337/6096, 2012, 816.

<sup>2</sup> This is an abbreviation of Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) and CRISPR-associated RNA-guided endonuclease Cas9. See, J.A. DOUDNA, E. CHARPENTIER, *The New Frontier of Genome Engineering with CRISPR-Cas9*, in *Science*, 346/6213:1258096, 2014, 1077.

<sup>3</sup> National Academies of Sciences, Engineering, and Medicine, *International Summit on Human Gene Editing: A Global Discussion*, 2015.

<sup>4</sup> <https://bit.ly/3l3bxxy> (last visited 31/08/2021).

<sup>5</sup> E.S. LANDER, F. BAYLIS, F. ZHANG, E. CHARPENTIER, P. BERG, C. BOURGAIN, B. FRIEDRICH, J.K. JOUNG, J. LI, D. LIU, L. NALDINI, J. NIE, R. QIU, B. SCHOENE-SEIFERT, F. SHAO, S. TERRY, W. WEI, E. WINNACKER, *Adopt a Moratorium on Heritable Genome Editing*, in *Nature*, 567/7747, 2019, 165; National Academies of Sciences, Engineering, and Medicine, *op. cit.*

<sup>6</sup> T. SEREQUEBERHAN, *The Critique of Eurocentrism and the Practice of African Philosophy*, in P.H. COETZEE AND A.P.J. ROUX (eds), *Philosophy from Africa: A Text with Readings*, London, 2003.

manifests itself in the various views expressed by scholars and institutions in the West on various legal and ethical issues arising from HGE.<sup>7</sup>

The Eurocentric framing of ethical issues in the discourse on the governance of heritable genome editing at a global level may be observed in the dominant themes that have emerged from debates on this issue. For instance, positions advocated for by various actors in the West appear to be extremely mindful of the possibility of the use of CRISPR being somehow akin to the state-driven eugenics programs of early 20th century Britain, America and Germany, and thus view its use as morally reprehensible.<sup>8</sup> It is, however, worth noting that the weight of such concerns on people's attitudes towards heritable genome editing appears to be historically conditioned, as it varies in different cultural contexts. For instance, aversions to genetic technologies because they are akin to eugenics ostensibly do not to have as significant a bearing outside of America and Europe, with public opinion polls outside these areas showing a greater public openness to heritable genome editing.<sup>9</sup> Also, in the South African context, the choices made by prospective parents in selecting donor gametes are apparently not influenced by a comparable aversion to selecting for certain traits because of the approximation of such choices to eugenics, given that prospective parents in South Africa typically place significant weight on the educational attainment of donors.<sup>10</sup>

This freedom in parental choice is also reflected in South African law. Section 12(2) of the South African Bill of Rights provides that: "Everyone has the right to bodily and psychological integrity, which includes the right—(a) to make decisions concerning reproduction".<sup>11</sup> This right to reproductive autonomy has been held to include a person's right to make use of artificial reproductive technologies.<sup>12</sup> This general right includes, among others, (i) a woman's right to make use of artificial reproductive technologies if she so wishes, irrespective of whether there is a medical indication, (ii) a woman's right to elect to make use of male and female donor gametes, and (iii) a woman's right to select the gamete donor(s) based on a range of personal characteristics, such as race, hair color, eye color, educational attainment, that must legally be accessible to her.<sup>13</sup> Therefore, the observation above that prospective parents in

<sup>7</sup>To be clear, while the authors sometimes use the terms "Eurocentrism" and "the Western perspective" in similar ways, the terms are distinct. The relationship between the two terms is that the Western perspective on ethical and legal issues relating to is based on, and informed by, Eurocentrism. In other words, the former is a product of the latter.

<sup>8</sup><https://www.thenation.com/article/can-we-cure-genetic-diseases-without-slipping-into-eugenics/> (last visited 31/08/2021).

<sup>9</sup><https://www.geneticsandsociety.org/internal-content/cgs-summary-public-opinion-polls#igmdata> (last visited 31/08/2021).

<sup>10</sup> Expert opinion by Mandy Jacqueline Rodrigues, paragraph 20, in *AB v Minister of Social Development* 2017 (3) SA 570 (CC). Ms Rodrigues states as follows: «Based on my experience from counselling donor gamete recipients and their partners and guiding them through the process of gamete donor selection, I can add the following observations regarding the evaluation of donor characteristics by prospective parents, which might be because of our South African context. [...] Prospective parents place a particularly high value on donors' level of education».

<sup>11</sup> Constitution of the Republic of South Africa, 1996.

<sup>12</sup> *AB v Minister of Social Development* 2017 (3) SA 570 (CC). See: B. SHOZI, *Something old, something new: applying reproductive rights to new reproductive technologies in South Africa*, in *South African Journal on Human Rights*, 36/1, 2020.

<sup>13</sup> Regulations Relating to the Artificial Reproduction of Persons GN 175 of GG35099, 2/3/2012.

South Africa intentionally practice (non-state-enforced, liberal) eugenics when selecting gamete donors is not only a cultural phenomenon, it is the exercise of a legal right.

Also, the way in which the *in vitro* embryo is perceived in South African law is largely aligned with maximizing parental choice. An *in vitro* embryo is a legal object that is owned by the intended gestational mother.<sup>14</sup> This stands in contrast with the European legal position that affords dignity to the embryo.<sup>15</sup> In South African law, an *in vitro* embryo cannot be equated to a prospective child; rather, it is perceived as the biological material that may give rise to the prospective child.<sup>16</sup> Accordingly, when parents decide to do preimplantation genetic testing (PGT) on their *in vitro* embryos, they are selecting a desired genetic profile for their prospective child, in the same way that they will later select a desired school for their child. Clearly, the view that South African law has of the *in vitro* embryo facilitates parental choice and reinforces reproductive autonomy. Heritable genome editing will expand the scope of parental choice: Instead of just choosing between a number of randomly generated genetic profiles (from the chosen genetic contributors: the gamete donors), parents will be able to customize one (or more) of these genetic profiles (to the extent that is technically possible). Given the view that South African law takes of the *in vitro* embryo, an argument for policy that is against editing the embryo from a moral-status-of-the-embryo platform will be legally untenable. Similarly, given South African law's embrace of access to medically assisted reproduction—irrespective of medical indication—an argument for policy against embryo editing from a platform of preserving the natural human genome will ring as hollow as an argument that natural conception has some special value that ought to be preserved and protected against artificial reproduction. Such arguments are fundamentally misaligned with the South African legal position on these normative issues.

A well-established principle in South African law is that the ambit of rights expands in sync with advances in society. The Constitutional Court held as follows:

“Indeed, rights by their nature will atrophy if they are frozen. As the conditions of humanity alter and as ideas of justice and equity evolve, so do concepts of rights take on new texture and meaning. The horizon of rights is as limitless as the hopes and expectations of humanity”.<sup>17</sup>

<sup>14</sup> *Ibid* at regulation 18. See: D.W. THALDAR, *The in vitro embryo and the law: The ownership issue and a response to Robinson*, in *Potchefstroom Electronic Law Journal*, 23, 2020.

<sup>15</sup> *Oliver Brüstle v Greenpeace eV C-34/10*, EU:C:2011:669. See: D.W. JORDAAN, *Stem cell research, morality, and law: an analysis of Brüstle v Greenpeace from a South African perspective*, in *South African Journal of Human Rights*, 33, 2017, 429 – 451. Note, however, that the South African Medical Research Council in its *Guidelines on Ethics in Reproductive Biology and Genetic Research* (2002) bases its position that the embryo is «special» on the observation that «a portion of the population [...] believes that the right to life and dignity is applicable to human embryos». For a critical discussion of this apparent conflict between South African law and these ethics guidelines, see: D.W. JORDAAN, *Science versus antiscience: the law on pre-embryo experimentation*, in *South African Law Journal*, 124, 2007, 618 – 634.

<sup>16</sup> *Ex Parte KAF 2019 (2) SA 510 (GJ)*. See: D.W. THALDAR, *op. cit.*; D.W. THALDAR, B. SHOZI, *Procreative non-maleficence: A South African human rights perspective on heritable human genome editing*, in *CRISPR Journal*, 3, 2020.

<sup>17</sup> *Minister of Home Affairs v Fourie 2006 (1) SA 524 (CC)*.

Accordingly, in South African law, human heritable genome editing is likely to be perceived as an advance in society that merits a concomitant expansion of the right to reproductive autonomy, and which will therefore add to the scope of constitutionally protected parental choice.<sup>18</sup>

### 3. Context: The practical reality of momentous public health challenges

In the previous section, we highlighted how certain fundamental arguments routinely expressed in the global discourse on whether heritable genome editing is ethically or legally permissible are, to a material extent, a product of the historical legacy that has an influence on the Western outlook on the use of the morality and legality of genome editing technologies. Insofar as these perspectives have been put forward as universally applicable, there has been a failure to recognize the extent to which not only varying cultural perspectives, but also the practical conditions of other jurisdictions may justify a departure from what may be described as the mainstream “global” position on issues such as what applications of CRISPR ought to be permitted. We will expand on the arguments presently.

The extent of the Eurocentric tenor of the discourse on heritable genome editing may again be observed in the prominence of the idea of there being a morally significant distinction between the correction of a genetic defect in germ cells, which is perceived as *therapy*, and the modification of a normal, non-defective genome in germ cells, which is perceived as *enhancement*—with the latter being perceived as being more ethically dubious. This distinction is prefaced on there being no compelling reason for genetic enhancement to justify it, whereas the curing of genetic disorders is deemed as a sufficiently strong reason to justify the manipulation of the human genome at the germline level. This distinction has often been used as a mechanism for differentiating between permissible and impermissible application of CRISPR. For instance, it has been suggested that modifying the human genome to prevent children from contracting infectious disease such as HIV or TB is a genetic *enhancement*, and is therefore unnecessary and unethical<sup>19</sup>. Such a classification is problematic because while there may be no immediate healthcare imperative for genetic enhancement in the developed world, South Africa and other developing countries face a high infectious disease burden and challenges with public healthcare, and social, cultural, and economic factors have meant that existing treatment has been ineffective.<sup>20</sup> In the face of ongoing epidemics faced by millions of people in the developing world, the alleged moral distinction between “negative selection” and “positive selection” is unconvincing, and seems to be unduly influenced by the Western cultural bias against anything labelled as akin to eugenics. On the contrary, we propose that there is an ethical imperative to explore promising new biotechnologies—including heritable genome editing—to find solutions to the diseases that haunt humanity, for reasons we expand upon below.

<sup>18</sup> D.W. THALDAR, M. BOTES, B. SHOZI, B. TOWNSEND, J. KINDERLERER, *Human germline editing: Legal-ethical guidelines for South Africa*, in *South African Journal of Science*, 116/9/10, 2020; B. SHOZI, T. KAMWENDO, J. KINDERLERER, D.W. THALDAR, B. TOWNSEND, M. BOTES, *The future of global regulation of human genome editing: A South African perspective on the WHO Draft Governance Framework on Human Genome Editing*, in *Journal of Medical Ethics*, 2021.

<sup>19</sup> [https://arrige.org/wp-content/uploads/2021/07/ARRIGE\\_statement\\_geneeditedbabies-1.pdf](https://arrige.org/wp-content/uploads/2021/07/ARRIGE_statement_geneeditedbabies-1.pdf) (last visited 25/11/2021).

<sup>20</sup> <https://www.unaids.org/en/resources/documents/2020/human-rights-and-covid-19> (last visited 31/08/2021).

The world is currently in the midst of the Covid-19 pandemic. Travel bans, quarantines, lockdowns, and other emergency measures are the order of the day. In light of the urgency of combatting this global pandemic, states have implemented these measures, which in most other circumstances might be considered egregious violations of fundamental human rights. Understandably, this has raised concern from human rights advocates such as UNAIDS, who published a guidance document in which they urge policy decision-makers to take a human-rights centered approach to this global pandemic, which is driven by community engagement rather than attempts at authoritarian control.<sup>21</sup> While we agree that respect for human rights is necessary, even in these times, it is difficult to ignore the reality that measures to respond to the Covid-19 crisis will, invariably, entail impacting on, for instance, the freedom of movement of the individual by measures like state-mandated lockdowns. Few, however, would argue that these measures are not necessary or justified in the present context: Serious public healthcare threats provide a moral imperative for interventions, which, in different contexts, might be regarded as immoral or inappropriate.

Another important factor in the justification of these measures is that they are temporary: As the crisis subsides, normalcy can gradually return. However, one should remember that South Africa was already dealing with other ongoing epidemics before the arrival of Covid-19, such as TB and HIV/Aids. Hence, South Africa's pre- and post-Covid-19 "normal" will be radically different from the pre- and post-Covid-19 "normal" conceived in many other countries—certainly the West.

At the onset, South Africa's health system has already stretched itself far too thin, so there is less or no room to accommodate another epidemic. Although South Africa allocates a higher proportion of its budget to health than most countries with a comparable level of economic growth, it struggles to achieve much of its healthcare needs due to an elevated disease burden.<sup>22</sup> For instance, according to the WHO, in 2018, about 300,000 people in South Africa fell ill with TB and about 63,000 people died of TB WHO.<sup>23</sup> The incidence of TB in South Africa is 520 in 100,000.<sup>24</sup> In the African region as a whole, 2.5 million people became ill with TB in 2016, accounting for a quarter of new TB infections globally WHO.<sup>25</sup> Conversely, the prevalence of TB in Europe, for instance, is among the lowest in the world. From 2016 – 18, Italy's TB incidence was 6.5 in 100,000.<sup>26</sup> Effectively, South Africa, like many other developing nations, is in a state of a perpetual health crisis.

Accordingly, if heritable genome editing offers the promise of, for instance, mitigating the impact of this epidemic by offering parents the choice to have children with a resistance to contracting TB, South Africa (and many similarly situated countries) would have a strong reason to explore this. We do not suggest, as was claimed in the manuscript reporting on the alleged case of the first genetically modified twins in China, that CRISPR is a tool by which we can "control the HIV epidemic", or any epidemic for

<sup>21</sup> *Ibid.*

<sup>22</sup> [http://spii.org.za/wp-content/uploads/2018/02/Right-to-Health-care\\_2017.pdf](http://spii.org.za/wp-content/uploads/2018/02/Right-to-Health-care_2017.pdf) (last visited 31/08/2021).

<sup>23</sup> <https://apps.who.int/iris/bitstream/handle/10665/329368/9789241565714-eng.pdf?ua=1> (last visited 31/08/2021).

<sup>24</sup> T. KOOTBODIEN, K. WILSON, *Tuberculosis Mortality by Occupation in South Africa, 2011 – 2015*, in *International Journal of Environmental Research and Public Health*, 15/2756, 2018, 1.

<sup>25</sup> *Ibid.*

<sup>26</sup> <https://www.statista.com/statistics/814016/number-of-cases-of-tuberculosis-in-italy/> (last visited 31/08/2021).

that matter, as it has already been pointed out that eliminating disease in this way would take decades, and would likely be less feasible than conventional methods of treatment.<sup>27</sup> Rather, we suggest that the high TB mortality rates, as well as the ineffectual efforts to minimize South Africans' default on TB treatment (which often leads to multi-drug resistant TB) provide morally compelling reasons for the state to allow parents the opportunity to have children who will be resistant to these very serious harms. Arguments based on abstract ideas of the "sanctity" of the human genome, or (its secular version) the "right" to an unaltered/natural genome, are simply out of touch with the concrete life and death challenges that South Africans face. As is the case with Covid-19 currently at a global level, heritable genome editing in South Africa may, in the future, be justified by the premise that serious public healthcare threats provide a moral imperative for healthcare interventions, which, in different contexts, might be regarded by some as immoral or inappropriate.

With that said, it is worth considering the question: Can heritable genome editing ever be used on a mass scale in the same fashion as a vaccine? To accomplish this, it would need to be emancipated from the IVF laboratory to the editing of *in utero* embryos through a minimally or preferably non-invasive intervention. Although the possibility of *in utero* editing is still undetermined, several preclinical studies have been conducted in respect of *in utero* therapeutic applications of gene therapy. These studies—conducted in diverse animal models, including pregnant mice,<sup>28</sup> rats,<sup>29</sup> and sheep<sup>30</sup>—have provided experimental evidence that *in utero* gene delivery for the treatment of various heritable diseases is feasible. Noteworthy is a study on the *in utero* delivery of gene therapy in pregnant guinea pigs to develop treatment for fetal stunted growth.<sup>31</sup> Pregnancy in guinea pigs is regarded as closely related to humans, in respect of the manner in which the placenta develops, as well as their newborn's degree of maturity.<sup>32</sup> As such, the ever-growing advancements in prenatal medicine together with the proliferation of animal studies, open doors for the possibility of *in utero* heritable genome editing.

Is the thought of using the mass rollout of non-invasive *in utero* heritable genome editing to prevent contracting TB—or Covid-19—far-fetched? If the technology is safe and effective, and if mechanisms can be put in place to make sure that this technology is made as widely available as possible, we suggest it is justifiable—at least in the South African context. In such a future scenario, it may well be that heritable genome editing becomes an important weapon in South Africa's fight against the lethal and persistent epidemic of TB—as well as new and evolving epidemics. It might become a genetic "vaccine".

<sup>27</sup> <https://www.technologyreview.com/s/614764/chinas-crispr-babies-read-exclusive-excerpts-he-jiankui-paper/> (last visited 31/08/2021).

<sup>28</sup> S. NAKAMURA, S. WATANABE, N. ANDO, M. ISHIHARA, M. SATO, *Transplacental Gene Delivery (TPGD) as a Noninvasive Tool for Fetal Gene Manipulation in Mice*, in *International Journal of Molecular Sciences*, 20/23, 2019, 1.

<sup>29</sup> C. COUTELLE, M. THEMIS, S.N. WADDINGTON, S.M.K. BUCKLEY, *Gene Therapy Progress and Prospects: Fetal Gene Therapy – First Proofs of Concept – Some Adverse Effects*, in *Gene Therapy*, 12/26, 2005, 1601.

<sup>30</sup> C.D. PORADA, P.J. PARK, G. ALMEIDA-PORADA, *Gestational Age of Recipient Determines Pattern and Level of Transgene Expression Following in Utero Retroviral Gene Transfer*, in *Molecular Therapy*, 11/2, 2005, 284.

<sup>31</sup> <https://www.rvc.ac.uk/research/about/animals-in-research/case-studies/developing-a-treatment-for-foetal-growth-restriction> (last visited 31/08/2021).

<sup>32</sup> *Ibid.*

#### 4. Conclusion

All this serves to illustrate that heritable genome editing raises several value-laden questions that can often elicit intense emotional responses, and that the way in which these questions are responded to is to no small extent influenced by factors such as the culture of a particular group or country. It is for this reason that categorical claims about the morality of modifying the human genome that are routinely expressed as worthy of being aspects of the global governance framework are problematic. Those who make such claims place reliance on purportedly universal norms like human nature or dignity, but these claims are often rooted in Western perspectives of morality. Thus, their application outside of this domain raises serious concerns of ethical imperialism. For instance, calls for a global moratorium on heritable genome editing research, although convincing to some, aim to enforce one (narrow) ethical perspective on everyone. In our view, a moratorium on research on heritable genome editing may unjustly privilege abstract concerns over the concrete suffering of future generations. In contrast, we suggest that the appropriate approach to heritable genome editing research is to encourage it within a clear regulatory framework, and that doing so would be in the best interests of prospective persons.<sup>33</sup> It is accordingly of critical importance that any contemplated global governance policy on heritable genome editing should be sufficiently broad to accommodate the diversity in how universal values are contextually understood and weighed in different countries.<sup>34</sup>

<sup>33</sup> D.W. THALDAR, M. BOTES, B. SHOZI, B. TOWNSEND, J. KINDERLERER, *op. cit.*; B. SHOZI, T. KAMWENDO, J. KINDERLERER, D.W. THALDAR, B. TOWNSEND, M. BOTES, *op. cit.*

<sup>34</sup> B. SHOZI, T. KAMWENDO, J. KINDERLERER, D.W. THALDAR, B. TOWNSEND, M. BOTES, *op. cit.*