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Challenges in Medical Ethics:

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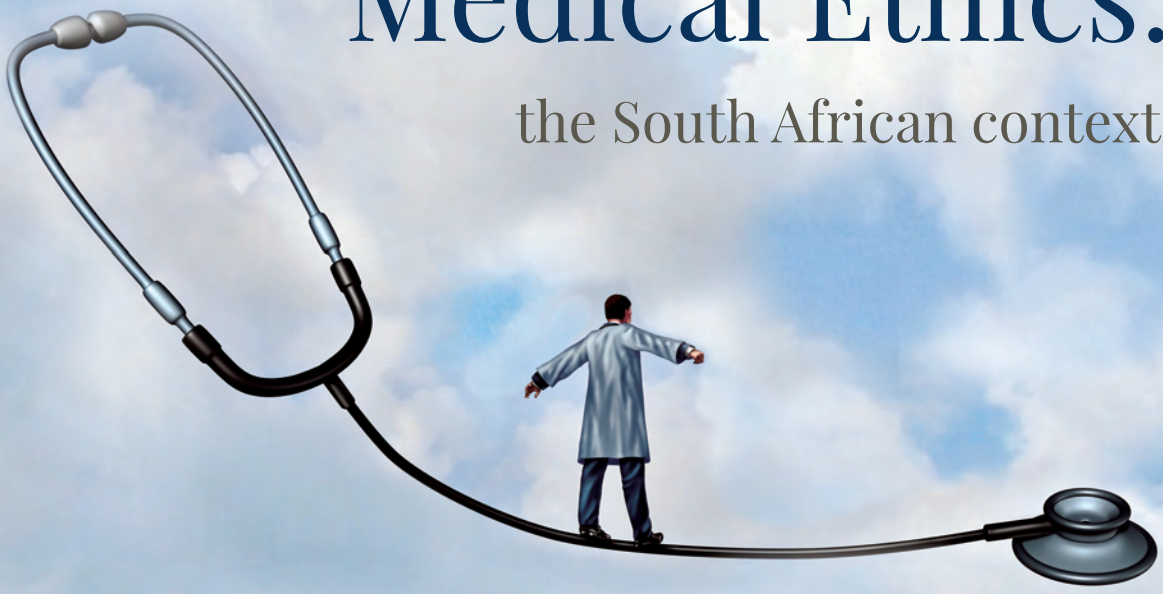

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14

How will Biotechnology Transform Human Health?

The peril and promise of genetic engineering

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Keywords: biotechnology; genetic engineering; genetic enhancement; genetic therapy; human nature; inequality; risk

14.1 INTRODUCTION

Technological advancement often gives rise to novel ethical problems. Technology opens up new possibilities, in that it allows us to do things which we have not been able to do before, and as a result, it inevitably raises the question as to whether these are things we *ought* to be doing, and if so, whether our prevailing moral norms and principles are adequate to deal with our new abilities. This is as true in the context of health care as elsewhere. Consider the development of life support technologies such as the medical ventilator, and the ethical questions this raised as to the extension of the concept of 'death' (Nair-Collins & Miller, 2017). More recently, the implementation of machine learning as a diagnostic and predictive tool in clinical medicine (Char, Shah & Magnus, 2018) and the use of big data analysis in biomedical contexts (Knoppers & Thorogood, 2017) have provoked ethical debate. The same is true of *biotechnological* development in medicine.

Biotechnology is defined by the Organisation for Economic Co-operation and Development (OECD) as "[t]he application of science and technology to living organisms, as well as parts, products, and models thereof, to alter living or non-

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living materials for the production of knowledge, goods and services" (OECD, 2013:156). The best known and probably most contentious possible application of biotechnology in the context of health care is genetic engineering. Genetic engineering involves the modification of a biological organism's DNA. Genetic engineering in humans may be carried out in germline or somatic cells,[1] and might be carried out for therapeutic purposes (genetic therapy) or to improve upon normal human functioning (genetic enhancement). This application of biotechnology holds great promise. The development of CRISPR/Cas9 technology, for example, creates exciting possibilities for the treatment of various forms of cancer, as well as cardiovascular, metabolic, haematological, and other hereditary diseases (Li et al., 2020). Some genetic therapies have already been approved by the US Food and Drug Administration (FDA) and the European Medicines Agency (EMA) to treat devastating monogenetic diseases such as spinal muscular atrophy (Chaytow et al., 2021). To many, however, the prospect of the development and use of interventions which aim to manipulate our genetic makeup evokes discomfort or repugnance, particularly when such interventions aim not only to treat but also to enhance. Some contend that these technologies represent a threat to the human species, or fear that their potential for harm may outweigh any positive consequences.

In what follows, I will outline the bioethical debate surrounding genetic engineering.[2] I will firstly consider two groups of arguments against the development and use of gene editing technologies which focus on (1) the inherent nature of genetic modification itself and its relationship to human nature, and (2) the likely consequences of gene editing. I will explore possible lines of defence against these challenges. Finally, I will briefly put forward the case that both genetic therapy and some forms of genetic enhancement hold great potential for the transformation of human health, and, in the case of enhancement, human well-being more generally. We should therefore be cautious of rejecting these technologies out of hand.

1 Ormond et al. define somatic gene editing as "the alteration of cells that cannot contribute to gamete formation and thus cannot be passed on from the individual to offspring" and germline gene editing as "genome editing that occurs in a germ cell or embryo and results in changes that are theoretically present in all cells of the embryo and that could also potentially be passed from the modified individual to offspring" (2017:69).

2 This overview is partially based on research completed as part of my PhD dissertation (Hall, 2012).

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14.2 GENETIC ENGINEERING AND HUMAN NATURE

Genetic engineering is aimed at the manipulation of the human genome. Many people feel uneasy about this prospect, as it seems to strike at a fundamental aspect of our common humanity. The concern is that modifying our genes will necessarily involve or lead to the modification of human nature, either because it represents a threat to our species membership, or because it will undermine values and attitudes that are regarded as foundational to our uniquely human identities. Arguments of this kind take issue with both the means (in the case of genetic engineering in general) and goals (in the case of genetic enhancement in particular) of the modification of the human genome.

14.2.1 The threat to species membership

The concern that genetic engineering will modify our genetic identities in such a way that we (or at least some of us) will no longer be members of the human species is largely focused on the possibility that this may weaken or undermine human commonality and threaten our recognition of the moral status of others. George Annas, for example, worries that "altering our nature necessarily threatens to undermine both human dignity and human rights" (2000:772) – a position also shared by Fukuyama (2002:101) – and calls for an "international treaty banning specific 'species altering' techniques and species-endangering experiments" (Annas, 2000:779). The purported link between species membership and moral status is emphasised in the Universal Declaration on the Human Genome and Human Rights in the statement that the "human genome underlies the fundamental unity of all members of the human family" (UNESCO, 1997:3). This implies that the modification of the human genome via genetic engineering could imperil this fundamental unity, and thereby our recognition of the moral status of others.

This argument also encompasses anxiety about posthumanism. Again, this concern is based upon the idea that genetic engineering will transform human nature to the extent that enhanced individuals will no longer be categorised as members of the species *Homo sapiens*. The worry is that the boundaries that currently determine membership of the human species will be eroded as two "subspecies" (Sandel, 2007:15) emerge: humans who maintain their naturally given genetic characteristics, and genetically modified posthumans. This development, some suggest, could further destabilise our "sense of moral community" based on common species membership (Buchanan et al., 2000:95) and may lead to what Agar refers to as "polarization" (2004:134) between humans and genetically engineered posthumans.

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While we may accept the possibility that genetic engineering could alter the human genome in ways which ultimately alter the human species, we need not agree that this is morally problematic. The human genome is, after all, subject to evolutionary forces, and will continue to change in the future. It is therefore unclear precisely why random change exacted by evolution should be preferable to directed change exacted by human interventions if it cannot be shown that the latter is considerably riskier than the former (Buchanan, 2011:137; Caplan, 2009:202; Harris, 2007:34). In other words, if genetic engineering entails a move away from what we currently regard to be human nature, based on our genetic characteristics, this will merely constitute a hastening of a process that will occur in any case as a result of evolution.

But what of the argument that genetic modification may, in its potential to undermine species membership, also threaten the basis of our recognition of moral status, human dignity, and by extension, universal human rights? Commentators respond to this assertion by questioning whether human nature, as the basis of moral recognition and human rights, can be reduced to brute biological characteristics. Rather, "[t]here are many candidates for the qualities that serve to give us our inalienable rights … but none hinge on a taxonomic designation" (Juengst, 2009:52). Theories of human rights usually regard such rights as stemming not simply from our genetic identity as human beings, but rather from the presence of interests, in that morally relevant beings have an interest in being treated in particular ways. While we might feel intuitively that "all humans have 'human rights' precisely because they are human", an interrogation of this idea reveals that it is "problematic as a theory of moral status" (Beauchamp & Childress, 2009:68). Rather, we are inclined to grant moral status and rights to those beings which have certain capacities such as the ability to reason, to form a conception of themselves as the subject of autonomous action, and to engage in moral deliberations, and while such qualities usually correspond with human species membership, this is neither a necessary nor a sufficient condition for our recognition of such moral status (Beauchamp & Childress, 2009:68).

To deny the conception of rights outlined above and to insist instead that moral status is bestowed upon us solely as a result of our genetic identity as human beings is to indulge in what Peter Singer refers to as "speciesism" (1993:88): the belief that moral status is conferred by the brute fact of our membership of the human species, based upon a prejudice in favour of our own kind. This amounts, according to Juengst, to the "moral idolatry" of the human genome (2009:52). If such a conception of moral status is unreliable, and moral status depends instead upon the presence of morally relevant characteristics, this implies that genetic

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engineering, despite its potential to erode the current boundaries of species membership, need not represent a threat to our recognition of the moral status or rights of others.

14.2.2 The threat to human values

The second concern with respect to genetic engineering, and genetic enhancement in particular, is that it will undermine or come into conflict with *attitudes* or *values* that we regard as foundational to our humanity, and that this will have a dehumanising effect on genetically modified individuals and on society as a whole. The concern in this case is not the threat to the genetic basis of species membership, but to the values and attitudes that give meaning to our humanity (Fenton, 2008:3). In other words, the dehumanising effect attributed to genetic engineering is related to its posited potential to undermine those values and attitudes which are regarded as constitutive of human nature, or which give content to our notion of "what it means to be human" (Robert, 2005:28).

14.2.2.1 Giftedness

The first value which is thought to be threatened by the prospect of genetic engineering is the value of 'giftedness'. Both Leon Kass (2003) and Michael Sandel (2007) suggest that the goal of genetic enhancement in particular is problematic because it constitutes a striving towards mastery of the natural world, and, more importantly, of ourselves. In so doing, it undermines our appreciation of the "giftedness" of our natural human abilities and endowments (Sandel, 2007: 26-27). This 'giftedness' entails a recognition that our abilities are "not wholly our own doing, nor even fully ours": a recognition that fosters an attitude of "humility" (Sandel, 2007:27). If we develop the ability to shape our genetic capacities, these could no longer rightly be regarded as "gifts for which we are indebted" but would instead be perceived as "achievements for which we are responsible" (Sandel, 2007:86-87). Leon Kass, the onetime chairman of The President's Council on Bioethics, echoes these sentiments, regarding an attitude of "hubris" as central to the project of genetic enhancement (Kass, 2003:18).

However, as Kass notes, the difficulty which such an argument immediately encounters is that we typically do not humbly accept the "giftedness" of disease and dysfunction (Kass, 2003:19). What Kass therefore seeks to argue is that there is something morally objectionable about the drive to enhance human nature that does not apply to medical treatment in general. Kass attributes this to the attitude expressed in genetic enhancement "that seeks wilful control of our own nature" and contrasts this with medicine as "servant and aid to nature's own powers of healing" (Kass, 2003:18), a point which Sandel echoes:

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> Although medical treatment intervenes in nature, it does so for the sake of health, and so does not represent a boundless bid for mastery and domination. Even strenuous attempts to treat or cure disease do not constitute a Promethean assault on the given. The reason is that medicine is governed, or at least guided, by the norm of restoring and preserving the natural human functions that constitute health. (Sandel, 2007:46-47)

One may, however, question the contention that intervening in our own natures to bring about enhancement constitutes hubris, while intervening in our own natures to cure or prevent disease or dysfunction does not. Buchanan, for example, argues that it is simply illogical to assert that it is acceptable to transform the given when it comes to curing disease and dysfunction, but not when it comes to improving normal functioning (Buchanan, 2011:3). In his view, it does not follow from the fact that "one ought to be appreciative of the good things one has and aware that many of them are unearned" that "one should refrain from ever trying to improve one's life or the lives of others" (2011:3). Harris echoes this point in his failure to be persuaded by the argument that we should accept the "gifted nature" of human talents but not the giftedness of disease and disability (Harris, 2007:112). Both Kass and Sandel argue that the distinction between treating disease and enhancing function lies in the fact that medical practice aids or restores natural human functioning. Harris, however, points out that disease and disability are themselves an aspect of natural human functioning (2007:35). Thus, the rejection of interventions that seek to manipulate nature would seem to exclude the practice of medicine altogether.

It is also important to note that it is not only through the practice of medicine that we routinely seek to exercise "wilful control over our own nature" (Kass, 2003:19). Attempts to master nature, and specifically, attempts to act upon and improve our own natures and the natures of others, are hardly novel pursuits: they are constitutive not only of the goals of medicine, but also of law, childrearing, and education, and the striving towards improvement and enhancement has always been a project which characterises human life (Buchanan, 2011:xi). In fact, the whole history of human culture and civilisation may be regarded as the history of human attempts to alter and shape the naturally occurring state of affairs, including our naturally occurring human natures: we have "long tinkered with ourselves using all manner of technologies from clothing to medicines to agriculturally produced food to telescopes to computers to airplanes" (Caplan, 2009:202), and in this sense, "Sandel's warning that one should not imperil giftedness comes several millennia too late" (Buchanan, 2011:79).

One may also question whether the genetic engineering of human beings is self-evidently motivated by a desire for mastery. All such interventions cannot be

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assumed, without further argument, to be necessarily driven by a desire for mastery or for total control over the given world, and as such, the argument against enhancement based upon this premise fails (Buchanan, 2011:79), as it involves a "vast empirical generalization … about the psychology of those who pursue enhancement" (Buchanan, 2011:9). In other words, it is perfectly feasible that one may seek to improve upon some aspect of human genetic functioning without thereby seeking, or expecting to achieve, mastery over the natural world or over our own natures.

14.2.2.2 The structure of agency and the value of effort

Michael Sandel advances a further objection to genetic engineering which focuses on the means which this technology would employ. In his view, "[o]ne aspect of our humanity that might be threatened by … genetic engineering is our capacity to act freely, for ourselves, by our own efforts, and to consider ourselves responsible – worthy of praise or blame – for the things we do and for the way we are" (Sandel, 2007:25). In other words, our achievements could no longer be regarded as flowing (entirely) from our own efforts but would rather be the result of technological achievement. Sandel's point here is related to the value we ascribe to the effort which we expend in achieving our goals. Genetic enhancement in particular has the potential to bypass the "substantial discipline and effort" which we currently invest in our attempts to "produce the desired feature or capability" and negates the fact that "a valued human activity is [sometimes] defined in part by the means it employs, not just by the end at which it aims" (Brock, 1998:58). We ascribe virtue to the means which are employed when our advantages are acquired through effort and hard work, and therefore regard the resulting advantages as honourable and deserved. The advantages that could be acquired through genetic enhancement, however, could be regarded as unmerited, as they are not acquired through such virtuous means (Mehlman, 2003:112).

However, one may object to this account of the value of effort, and the extent to which this value is likely to be compromised by genetic engineering. As Harris points out, many enhancing technologies "leave plenty of room for effort, skill training [and] hard work" (2007:133). The causal relationship between genetically modified genotypes and phenotypes (the eventual characteristics or traits of an organism) will vary, and will depend upon environmental influences, including one's own actions and efforts, a point which Sandel concedes in his assertion that "the roles of effort and enhancement will be a matter of degree" (2007:25). While enhanced individuals may be engineered for high levels of intelligence, for example, this genetic disposition is worthless without education, with all the associated effort in terms of study and discipline which that implies.

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Allhoff (2005) also makes two points in opposition to the argument against genetic engineering from the value of effort. Firstly, he points out that "successive generations have always had more resources available to them than previous generations", and that we routinely expend less effort in the achievement of our goals than our ancestors. Motorised transport, technological study aids, and domestic appliances, among other technologies, have greatly reduced the effort and transformed the means by which we realise our ends. We do not regard this as problematic, or the ultimate achievement of our goals as any less laudable as a result. Secondly, he points out that some people, due to their genetic advantages as provided by the genetic lottery, do not need to expend as much effort to achieve their objectives as others. We do not regard their accomplishments as any less valuable, or any less their own, despite this (2005:46). Genetic engineering therefore does not seem to represent an unprecedented departure from the existing state of affairs. Taken together, these counter arguments suggest that such technologies would not represent the kind of novel disruption to human agency that critics of enhancement suggest it would.

14.2.2.3 The goodness of fragility

A further objection to genetic engineering which focuses on its purported threat to human values concerns the value of fragility. Human beings are by nature vulnerable creatures, and are susceptible to misfortune, adversity, disease, and disability. Some have expressed the concern that the revolutionary potential of genetic engineering to reduce or nullify this human fragility is morally problematic. The reasoning behind this position is that the physical and mental frailties of human beings, which will be the targets of such technologies, are in fact valuable aspects of the human condition, or, in other words, that "the limitations" which our bodies impose upon us with regard to the achievement of our goals "might have ethical significance that [will be] imperilled by efforts … to overcome all such limitations" (McKenny, 1998:223). Winkler argues in this regard that the "power over uncertainty or contingency" (1998:242) which enhancement technologies offer us could lead to a sacrifice of our "full humanity" (1998:248), as this humanity is partially constituted by a tendency to "love and honour the body in all its fragility, imperfection and finitude" (1998:249).

Why should we feel that the fragility of the body is something to be valued, taking into account that much of the history of civilisation represents an attempt to overcome it? One of the principal answers offered in reply to this question is that the experience of our frailty and vulnerability makes possible important modes of "self-formation" in our responses to adversity (McKenny, 1998:235). Our failure to recognise "the goodness of fragility" (Parens, 1995:141), then, will

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actually impoverish rather than improve human beings by, for example, obliterating the experience of caring for others who are more vulnerable than ourselves, or by removing the opportunity to develop capacities of perseverance and forbearance in response to our own finitude.

There are several problems with this objection to genetic engineering. Firstly, the modification of the human genome will not lead to heaven on earth. Genetic engineering will not make us invulnerable, and nor will it remove all adversity or contingency from our lives (Buchanan, 2011:81; Savulescu, 2007:287). Is it nonetheless problematic that genetic engineering is at least *directed towards* the eradication of human fragility, even if this is a goal which can never be completely accomplished?

The difficulty here is that the insistence upon the value of human fragility is based upon a particular world view which is not universally shared. Some insist, for example that it is not "intuitively obvious that there is necessarily … anything good about aging, or death, or human fragility" (Allhoff, 2005:45). This is borne out by the fact that the use of multiple technologies to counteract such frailty has been regarded as morally laudable over the course of history, and it is unclear why genetic interventions should be an exception to this. Savulescu characterises positions which reject genetic modifications on the basis that they would reduce human frailty as expressing the warped argument that "because life is unpredictable, and good can come out of bad, we should choose the bad or be indifferent to it, or allow it to occur … when we can easily and foreseeably avoid it" (Savulescu, 2007:286). On this account, the restriction of genetic engineering based on a particular world view which values fragility would be "tyrannical" in the face of competing conceptions of the good life which do not regard it as something which ought to be preserved (Harris, 2007:137). In addition, there is something deeply worrying about any position which seeks to maintain the fragility of *others* in order to preserve the self-formation that accompanies the experience of caring for them.

Thus far it appears that the transformation of human nature via genetic engineering, either in terms of our genetic species identity or the values which are central to our humanity, is either exaggerated or less ethically concerning than it first appears. It is worth emphasising again that attempts to alter human nature are hardly new. Human nature has not only been subject to change through evolutionary processes, but also through our own environmental interventions (Daniels, 2009:33). Compared to human beings of the not-too distant past, today "we are taller, we live longer, we have more inclusive ethical codes" (Lewens, 2009:354). These are changes that are at least partially the result of human action,

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including the use of technological interventions. By this token, genetic engineering is not necessarily a radical departure from what has come before, but rather the latest phase on a continuum of interventions that seek to improve upon human functioning. However, there is a further set of arguments against genetic engineering which I have not yet considered. What if the consequences of genetic engineering are not improvement, but disaster, or what if its benefits are outweighed by far greater costs? It is to these possibilities that I now turn.

14.3 CONSEQUENTIALIST ARGUMENTS AGAINST GENETIC ENGINEERING

Consequentialist arguments against genetic engineering hold that there are negative consequences which are likely to follow from genetic modification, and as these consequences are ethically undesirable, we should avoid them by refraining from developing and utilising such technologies. There are two possibilities that are frequently identified in this regard. On the one hand, genetic engineering, despite the benefits that it might appear to offer, may also have negative consequences for the person who is targeted by the intervention. Here the primary concern is that these technologies may not be safe, and that the inherent risks of genetic engineering are greater than conventional forms of medical treatment due to the nature of genetic functioning. On the other hand, one may accept that genetic engineering may benefit the targeted individual, but still hold that its use would be bad for society as a whole. Here, the most commonly stated worry is that inequitable access to such technologies will exacerbate social and global inequalities, and lead to injustice.

14.3.1 Genetic engineering is medically hazardous

The worry that genetic engineering may be medically hazardous is frequently expressed (Anderson, 1989:686; Borenstein, 2009:524; Kamm, 2009:127; Kass, 2003:14; Mehlman, 2003:71; The President's Council on Bioethics, 2003:48), and ought to be taken seriously. While the possibility of dangerous and unforeseen side effects is always a relevant concern with respect to new medical procedures, genetic engineering may be particularly vulnerable to such concerns. The pleiotropic nature of genes, in that most genes appear to have more than one function and to affect more than one body system (Coors & Hunter, 2005:21), implies that it may be difficult for researchers to predict the effect of a given genetic intervention. Coors and Hunter draw our attention to an incidence of genetic intervention in mice, which caused over-expression of the p53 gene. This intervention reduced the incidence of cancer in the affected mice, but also significantly lessened their life expectancy (2005:21). This example illustrates the danger that "even modest alterations in the best studied genes … can have

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completely unexpected consequences for aspects of the organism that were not at all suspected to be related to the function of the gene" (Coors & Hunter, 2005:22). This risk is amplified by the polygenic nature of most complex human traits and disorders which would likely be the targets of enhancement interventions and many therapeutic interventions respectively.

A second point which is raised in support of the particularly hazardous nature of genetic engineering has to do with the inheritability of germline genetic interventions. Genetic interventions are usually classified as somatic cell or germline interventions. Somatic cell genetic interventions (whether therapeutic or enhancing) entail "the insertion of a … gene into somatic, or body, cells of a patient", while germline interventions, often viewed as more controversial, aim at genetic alterations at the level of the "gametic cells" in such a way that "children of the patient would receive the [altered] gene" (Anderson, 1989:682). Germline genetic interventions, even in their therapeutic manifestations, are unique technological interventions in that their effects would not be limited to the treated patient, but would be passed onto their offspring (Brock, 1998:62). Where the safety of a particular intervention has not been established, or, more pertinently, where unforeseen negative effects of an intervention are delayed, the future person may be harmed by a genetic intervention which affects them but which they have not consented to. This may be a good reason to avoid at least germline genetic interventions until safety can be definitively established.

However, the fact that a procedure is risky does not necessarily give us reason to disavow it entirely, particularly if its potential benefits would be very great, and for this reason, medical risk may not be a knock-down argument against the practice of genetic engineering. While safety concerns, particularly with regard to new and revolutionary interventions, should always be at the forefront of researchers' minds, this suggests the need for the utmost caution, but does not necessarily imply that an outright ban on genetic engineering is justified (Baylis & Robert, 2004:14). If genetic interventions are inherently more risky than other novel medical interventions, they ought to be approached with greater caution. However, if it can be shown, through extended and careful research, and controlled clinical testing, that genetic interventions can overcome the difficulties identified above, and could be practiced in a relatively safe and effective manner, this objection simply disappears.

In addition, the possible effect of germline genetic engineering on future generations is not unique to such interventions. As Moseley points out, "[h]umans alive today do many things which may have unforeseeable and negative consequences for future generations but which appear ethically acceptable" and that normal

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procreation in general is subject to this very same complaint (Moseley, 1991:643). If we assume that rational persons will not choose interventions that run clear risks of bringing about obviously negative consequences for their offspring and descendants, we cannot reject genetic interventions purely on the basis of remote risks which have not been proven without calling into question many other human practices, especially in the realm of scientific interventions, which we currently consider to be not only ethically acceptable, but desirable. As Harris points out, "insistence on rigorous risk assessment and on only proceeding if in all the circumstances of the case the risks are acceptable is a feature not only of all medical and scientific advance but of all human decision making whatsoever" (2007:33). Thus, while the risks of genetic engineering must be taken very seriously, the presence of such risks does not constitute a definitive argument against this practice.

14.4 GENETIC ENGINEERING AND INJUSTICE

The concern that genetic engineering may lead to or exacerbate injustice is situated within the framing assumption that the benefits of genetic engineering primarily accrue to the individual, and that this benefit should be balanced against the likelihood of its "social or collective harms" (Buchanan, 2011:36). The worry here is that genetic engineering, and particularly genetic enhancement, will bring about or widen inequalities between individuals and groups in society in a way which will be unjust. If, as is likely, genetic engineering is at least initially an expensive intervention which is not covered by national health schemes or health insurance, only those who are already financially advantaged will be able to make use of it. If these genetic interventions confer "advantages in competitions for social goods such as wealth, status or power" (Gardner, 1995:69), this improved ability to compete will therefore increase the variance of the distribution of social goods (Gardner, 1995:74), contributing to "the widening gap between the well-off and the less-so" (Baylis & Robert, 2004:12).

The purported connection between genetic enhancement and injustice is not only relevant with regard to inequality within societies, but also inequality between societies (Mehlman, 2003:127). Concerns have already been expressed that the benefits of new biotechnological advances may not be made available in many African countries as a result of their prohibitive cost (Benatar, 1998:169). In countries where greater provision is made for access to health care beyond the primary level, it is likely that access to genetic engineering will be distributed more equitably among the population than in countries where only the wealthy will be able to fund it. The ethical issues at stake here are therefore not

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confined to the sphere of personal morality but are significant with respect to global bioethics. This is particularly relevant in the African context, where the distribution of health care resources, and particularly the just distribution of global health care resources, is already of major ethical concern. Research into genetic modification may represent a misallocation of resources in a context where the basic health needs of millions of people remain unfulfilled. We do not need genetic engineering to provide all children with mosquito netting or to vaccinate everyone against measles (Davis, 2009:149).

It may certainly be the case that access to genetic engineering technologies may be inequitably distributed, at least initially, and probably for some time. However, brute inequality does not necessarily imply injustice. For the inequality created by genetic engineering to be morally concerning, it must also be unjust. This raises some difficult questions, as the notion of justice itself is extremely difficult to define or to reduce to a single theory (Harris, 1992:192). However, some general remarks on this matter may suffice.

Firstly, we should note that rather than being born into equality, we are all already subject to the natural inequality imposed by the genetic lottery (Holtug, 1999:138). Some of us are naturally genetically advantaged competitors, and some are less fortunate (Brock, 1998:67). However, one may counter that this naturally given inequality is not the result of human action, and therefore not within the sphere of behaviour that can be morally censured. The situation with respect to genetic engineering is different. Here, what specifically concerns many is the possibility that sophisticated genetic therapies and enhancements would only be available to those in society who are already wealthy and powerful. The competitive advantages accompanying access to these technologies could therefore be bought in a way that natural genetic advantages cannot be.

Once again, however, we may question whether this really represents such a radical departure from the status quo. It is already the case that the financially advantaged can purchase competitive advantages. We are not only already subject to naturally occurring inequality as a result of the genetic lottery, but also to inequality brought about by expensive environmental enhancements available only to the wealthy. For example, private school education indisputably exacerbates social inequalities between the rich and the poor, as does inequitable access to the most sophisticated medical treatments. While we ought to be concerned by the possible inequality which may be caused by the future use of genetic engineering, we ought to be equally concerned with the vast inequalities that are already present in and between our societies, and that may clearly be deepened by the ability of the wealthy to purchase environmental enhancements and other

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competitive advantages. In addition, it is not necessarily the case that "[f]airness … require[s] that benefits should not be provided to any" until they are widely accessible (Harris, 2007:28).

Harris sums up this position as follows:

> So when enhancements make life or lives better they are justified if they do just that [even] if they also confer positional advantage that is no part of their justification and will in fact always constitute a moral disadvantage of their use, although whether this disadvantage constitutes a decisive argument against either the use or the permissibility of the enhancement will depend upon many other factors, among which are the degree of advantage, the degree of unfairness it creates, and the likelihood of the unfairness being minimized over time or by other factors such as compensation. (2007:30)

Another somewhat idealistic possibility is that modification of the human genome could be employed to diminish, rather than exacerbate, inequalities (Savulescu, 2006:321). How might this be so? Firstly, while genetic interventions may initially only be available to the wealthy, this may ultimately give way to a situation in which their distribution will be more equitable. Moore points out that the vast majority of new medical technologies are initially only available to the rich, but as they are further developed and refined, costs are lowered, and eventually "procedures that were once cost prohibitive are … available to everyone" (Moore, 2000:117).

Secondly, it has been suggested that genetic enhancement could be used to improve our ethical sensibilities through genetic means, in other words, that "genetic moral enhancement" (Faust, 2008:397) could be used to improve our sense of responsibility towards others, thus heightening our feelings of solidarity and our moral intuitions as to the demands of justice, rather than merely being used as a tool to gain a competitive edge over others.

Finally, some suggest that active use could be made of genetic modifications to counter or diminish the natural inequality that is the result of the genetic lottery, the results of which are "arbitrary from a moral perspective" (Rawls, 1971:64). If our natural genetic advantages and disadvantages are not something which we can be said to deserve (Rawls, 1971:86), an argument can be made for the redistribution of genetic goods by the means of both genetic therapy and enhancement, favouring not the wealthy and powerful, but those who are worse off, genetically or otherwise. While this suggestion may be somewhat idealistic in terms of the current financially driven medical market, it does indicate that the obligation to reduce inequality can at least in principle be called upon as

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a motivating factor for the development and use of genetic engineering, rather than a factor militating against it. Holtug suggests in this regard that "people who are badly off through no fault of their own" (1999:42), for example, because of genetic disease, should be compensated via the provision of genetic therapy to satisfy the principle of justice.

This raises an interesting possibility. If the successful development of genetic engineering technologies results in a situation in which the "natural distribution" of abilities would no longer be "simply [a] natural fact" (Rawls, 1971:87) their distribution would rightly fall within the province of a theory of justice. Savulescu highlights various alternatives in this regard: "We can allow our lives to be determined by the natural lottery, or by wealth. Both of these lead to injustice." In contrast to this, he suggests that "[j]udicious use of enhancement, based on a rational policy" can, in fact, operate to reduce inequality and injustice (Savulescu, 2006:336).

Consequentialist arguments against genetic engineering rightly draw our attention to the possible negative outcomes of these technologies, including medical risks and the exacerbation of inequality and injustice. While we ought to take these concerns into account in making decisions about when and how to make these interventions available, it is also clear that the worries raised here do not apply only to genetic engineering, but also to other interventions such as environmental enhancements and novel medical treatments in general. Caution is appropriate, but the possibilities identified above are not sufficient to justify the outright rejection of genetic engineering. This is especially the case if we consider not only the possible negative consequences of genetic modification, but also its transformational promise.

14.5 THE PROMISE OF GENETIC ENGINEERING

Genetic therapies are already available for several disease conditions. For example, while they do not yet amount to a cure, three therapies designed to enhance SMN (survival motor neuron protein) production have recently been approved for the treatment of SMA (spinal muscular atrophy), a disease which causes muscles to become weak and waste away, and which predominantly affects children. In its most severe form, and left untreated, it leads to death before the age of two (Chaytow et al., 2021). The FDA has also approved genetic therapies for the treatment of cancers such as acute lymphoblastic leukaemia and lymphoma. Clinical trials are currently underway for the treatment of rare neurological diseases such as ALS (amyotrophic lateral sclerosis), a disease that affects the nerve cells responsible for controlling voluntary muscle movement, and for which

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there is currently no cure; for treatments to restore vision; and for treatments to combat sickle cell disease, among others. The potential of genetic therapy for reducing suffering and for restoring function in a way that expands opportunity is not something that we should dismiss based on misplaced repugnance.

What of genetic enhancement? While we should certainly take into consideration the moral concerns with enhancement discussed thus far, we should also consider the "cost of not making use of enhancement technologies" (Buchanan, 2011:37). While most would acknowledge the moral desirability of combatting disease and disability to restore normal functioning, we need not accept that this is as far as morality requires us to go. Normal functioning, as Buchanan notes "is simply functioning that is typical of the organism as it happens to be now", without reference to what we value (2011:3-4) and a tendency to prize normal functioning above all else is to "confuse human good with what evolution delivers" (Buchanan, 2011:4). Harris, too, fails to see why the achievement of normality should represent the limit of our moral ambitions. Rather, he argues that "the most usual motive for using technology to intervene in the natural lottery of life is for the sake of the harms this will prevent or the goods that this will bring about" (Harris, 2007:54). If particular forms of general-purpose genetic enhancements can be shown to increase the likelihood of leading a good life, contribute towards well-being, and reduce the disadvantages imposed upon us by the genetic lottery, such technologies may very well be compatible with these goals.

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Bibliography

Agar, N. 2004. *Liberal eugenics: in defence of human enhancement*. Oxford: Blackwell. https://doi.org/10.1002/9780470775004

Allhoff, F. 2005. Germ-line genetic enhancement and Rawlsian primary goods. *Kennedy Institute of Ethics Journal*, 15(1):39-56. https://doi.org/10.1353/ken.2005.0007

Anderson, W.F. 1989. Human gene therapy: why draw a line? *Bioethics*, 14(6):681-693. https://doi.org/10.1093/jmp/14.6.681

Annas, G.J. 2000. The man on the moon, immortality, and other millennial myths: the prospects and perils of human genetic engineering. *Emory Law Journal*, 49(3):753-782.

Baylis, F. & Robert, J.S. 2004. The inevitability of genetic enhancement technologies. *Bioethics*, 18(1):1-26. https://doi.org/10.1111/j.1467-8519.2004.00376.x

Beauchamp, T.L. & Childress, J.F. 2009. *Principles of biomedical ethics*. Oxford: Oxford University Press.

Benatar, S.R. 1998. A perspective from Africa on human rights and genetic engineering. In: J. Burley, (ed.). *The genetic revolution and human rights: the Oxford amnesty lectures 1998*. Oxford: Oxford University Press. 159-189.

Borenstein, J. 2009. The wisdom of caution: genetic enhancement and future children. *Science and Engineering Ethics*, 15(4):517-530. https://doi.org/10.1007/s11948-009-9183-9

Brock, D.W. 1998. Enhancements of human function: some distinctions for policymakers. In: E. Parens (ed.). *Enhancing human traits: ethical and social implications*. Washington, DC: Georgetown University Press. 48-69.

Buchanan, A. 2011. *Beyond humanity? The ethics of biomedical enhancement*. Oxford: Oxford University Press.

Buchanan, A., Brock, D., Daniels, N. & Wikler, D. (eds.). 2000. *From chance to choice: genetics and justice*. Cambridge: Cambridge University Press. https://doi.org/10.1017/CBO9780511806940

Caplan, A.L. 2009. Good, better, or best? In: J. Savulescu & N. Bostrom (eds.). *Human enhancement*. Oxford: Oxford University Press. 199-209.

Char, D.S., Shah, N.H. & Magnus, D. 2018. Implementing machine learning in health care: addressing ethical challenges. *The New England Journal of Medicine*, 378(11):981-983. https://doi.org/10.1056/NEJMp1714229

Chaytow, H., Faller, K., Huang, Y.T. & Gillingwater, T.H. 2021. Spinal muscular atrophy: from approved therapies to future therapeutic targets for personalized medicine. Cell reports. *Medicine*, 2(7):100346. https://doi.org/10.1016/j.xcrm.2021.100346

Coors, M.E. & Hunter, L. 2005. Evaluation of genetic enhancement: will human wisdom properly acknowledge the value of evolution? *The American Journal of Bioethics*, 5(3):21-22. https://doi.org/10.1080/15265160591002683

Daley, J. 2021. Four success stories in gene therapy. *Nature.* [Online]. https://doi.org/10.1038/d41586-021-02737-7

Daniels, N. 2009. Can anyone really be talking about ethically modifying human nature? In: J. Savulescu & N. Bostrom (eds.). *Human enhancement*. Oxford: Oxford University Press. 25-42.

Davis, D.S. 2009. From YUCK to WOW and back again. *Religious Studies Review*, 35(3):147-150. https://doi.org/10.1111/j.1748-0922.2009.01354.x

DeGrazia, D. 2005. Enhancement technologies and human identity. *Journal of Medicine and Philosophy*, 30(3):261-283. https://doi.org/10.1080/03605310590960166

Faust, H.S. 2008. Should we select for genetic moral enhancement? A thought experiment using the MoralKinder (MK+) Haplotype. *Theoretical Medicine and Bioethics*, 29(6):397-416. https://doi.org/10.1007/s11017-008-9089-6

Fenton, E. 2008. Genetic enhancement: a threat to human rights? *Bioethics*, 22(2):1-7.

https://doi.org/10.52779/9781991201959/14

Fukuyama, F. 2002. *Our posthuman future: consequences of the biotechnology revolution*. New York: Farrar, Straus and Giroux.

Gardner, W. 1995. Can human genetic enhancement be prohibited? *The Journal of Medicine and Philosophy*, 20(1):65-84. https://doi.org/10.1093/jmp/20.1.65

Hall, S. 2012. Harm and enhancement: philosophical and ethical perspectives. Unpublished doctoral dissertation. Stellenbosch: Stellenbosch University.

Harris, J. 1992. *Wonderwoman and Superman: the ethics of human biotechnology*. Oxford: Oxford University Press.

Harris, J. 2007. *Enhancing evolution: the ethical case for making better people*. Princeton: Princeton University Press.

Holtug, N. 1999. Does justice require genetic enhancements? *Journal of Medical Ethics*, 25(2):137-143. https://doi.org/10.1136/jme.25.2.137

Juengst, E. 2009. What's taxonomy got to do with it? "Species integrity", human rights, and science policy. In: J. Savulescu & N. Bostrom (eds.). *Human enhancement*. Oxford: Oxford University Press. 43-58.

Kamm, F. 2009. What is and is not wrong with enhancement? In: J. Savulescu & N. Bostrom (eds.). *Human enhancement*. Oxford: Oxford University Press. 91-130.

Kass, L.R. 2003. Ageless bodies, happy souls: biotechnology and the pursuit of perfection. *The New Atlantis*, 1:9-28.

Knoppers, B. & Thorogood, A. 2017. Ethics and big data in health. *Current Opinion in Systems Biology*, 4:53-57. https://doi.org/10.1016/j.coisb.2017.07.001

Lewens, T. 2009. Enhancement and human nature: the case of Sandel. *Journal of Medical Ethics*, 35(6):354-356.

Li, H., Yang, Y., Hong, W., Huang, M., Wu, M. & Zhao, X. 2020. Applications of genome editing technology in the targeted therapy of human diseases: mechanisms, advances and prospects. *Signal Transduction and Targeted Therapy*, 5(1):1-23. https://doi.org/10.1038/s41392-019-0089-y

McKenny, G.P. 1998. Enhancements and the ethical significance of vulnerability. In: E. Parens (ed.). *Enhancing human traits: ethical and social implications*. Washington, DC: Georgetown University Press. 222-237.

Mehlman, M. 2003. *Wondergenes: genetic enhancement and the future of society*. Bloomington, IN: Indiana University Press.

Moore, A.D. 2000. Owning genetic information and gene enhancement techniques: why privacy and property rights may undermine social control of the human genome. *Bioethics*, 14(2):97-119. https://doi.org/10.1111/1467-8519.00184

Moseley, R. 1991. Maintaining the somatic/germ-line distinction: some ethical drawbacks. *The Journal of Medicine and Philosophy*, 16(6):641-647. https://doi.org/10.1093/jmp/16.6.641

Nair-Collins, M. & Miller, F.G. 2017. Do the 'brain dead' merely appear to be alive? *Journal of Medical Ethics,* 43(11:):747-753. https://doi.org/10.1136/medethics-2016-103867

OECD. 2013. Biotechnology. In: *OECD Factbook 2013: economic, environmental and social statistics.* Paris: OECD Publishing.

Ormond, K.E., Mortlock, D.P., Scholes, D.T., Bombard, Y., Brody, L.C., Faucett, W.A., Garrison, N.A., Hercher, L., Isasi, R., Middleton, A., Musunuru, K., Shriner, D., Virani, A. & Young, C.E. 2017. Human germline genome editing. *American Journal of Human Genetics*, 101(2):167-176. https://doi.org/10.1016/j.ajhg.2017.06.012

Rawls, J. 1971. *A theory of justice*. Oxford: Oxford University Press. https://doi.org/10.4159/9780674042605

Parens, E. 1995. The goodness of fragility: on the prospect of genetic technologies aimed at the enhancement of human capacities. *Kennedy Institute of Ethics Journal*, 5(2): 141-153. https://doi.org/10.1353/ken.0.0149

Robert, J.S. 2005. Human dispossession and human enhancement. *The American Journal of Bioethics*, 5(3):27-29. https://doi.org/10.1080/15265160591002728

https://doi.org/10.52779/9781991201959/14

Sandel, M. 2007. *The case against perfection*. Cambridge & London: The Belknap Press of Harvard University Press.

Savulescu, J. 2006. Justice, fairness, and enhancement. *Annals of the New York Academy of Sciences*, 1093:321-338. https://doi.org/10.1196/annals.1382.021

Savulescu, J. 2007. In defence of procreative beneficence. *Journal of Medical Ethics*, 33(5):284-288. https://doi.org/10.1136/jme.2006.018184

Singer, P. 1993. *Practical ethics*. Cambridge: Cambridge University Press.

The President's Council on Bioethics. 2003. *Beyond therapy: biotechnology and the pursuit of happiness*. Washington, DC: The President's Council on Bioethics.

UNESCO. 1997. *Universal declaration on the human genome and human rights*. Paris: 29th Session of the General Conference.

Winkler, M.G. 1998. Devices and desires of our own hearts. In: E. Parens (ed.). *Enhancing human traits: ethical and social implications*. Washington, DC: Georgetown University Press. 95-123.

https://doi.org/10.52779/9781991201959/14