THE MORAL DEFENSIBILITY OF GENE THERAPY

How does Therapeutic Engineering Differ from the New Eugenics

Once the distinction between somatic cell and germ-line therapy has been dealt with, a larger question looms heavy over the realm of permissible genetic engineering. Some authors have attempted to divide genetic engineering into two categories, therapeutic and eugenic. It has been argued that therapeutic alterations would be permissible, whereas those which do not fall into this category, and are thus described as eugenic, should be banned. In reality, however, it is difficult, if not impossible, to draw a clean line between the two, thus it may be more fruitful to consider whether to allow either all genetic engineering, or ban any form.

A suitable meta-ethical framework would greatly enhance this discussion, so the question of which theory, if any, is capable of providing relevant normative guidelines is pertinent. The germane issue is the treatment of future humans within the context of the ethical theory. A contractarian theory, which draws normative conclusions from the assumption that moral agents agree on such norms irrespective of their station in life, as originally framed, pays no due to future agents. This theory can not be applied, because the moral bargaining takes place between current moral agents, and future humans have no representative at the table. A Kantian theory of universalisability relies too heavily on the predisposition of the moral agents, as opposed to the supposed inherent (dis)value in either form of genetic engineering. To clarify, within the Kantian framework, norms can be derived from the application of the following inference:

(1) If *X* is universalisable, then *X* is permissible/obligatory[1].
(2) *X* is universalisable.

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(3) *X* is permissible/obligatory.

Can this be applied to future humans? A candidate *X* can be derived which highlights the deficiency of this theory. Suppose *X* is 'No-one should suffer the effects of phenylkutenaria (PKU), thus they should receive *Y*' where *Y* is either gene therapy or some other form of therapeutic treatment, such as assistance with their special diet. It would seem that not many would deny *X*, but, just as with the contractarian model, this categorical imperative gives no

[1] Dependent on the exact form of the theory

basis for the treatment of future humans.

A utilitarian model, on the other hand, already provides a means of discussing future humans. One well-worn objection to flavours of utilitarianism that aim to maximise the total store of some value, such as happiness, is that this kind of utilitarianism would have everyone continually producing progeny. The greater the total number of moral agents, the greater the amount of overall value (in this case, happiness). This objection is more applicable to rule utilitarianism than act utilitarianism, and is not really applicable to the brands that espouse a 'per capita' brand of maximisation. In all cases this objection can be overcome by appealing to the notion that beyond a certain population density, the next person born into the world will not provide a net benefit. However, this is not the issue in question. More to the point, it has been shown that utilitarianism is framed in such a manner as to include future humans in the realm of moral considerability.

One approach is to treat therapeutic engineering as that which brings the subject to the norm of society, whereas eugenics attempts to elevate the subject beyond the norm. This approach is fraught with difficulty. Take for example height in humans, over the past millennium the average human height has definitely increased, what is more, the average human height differs dramatically across racial groups, so how can the norm be calculated. Also problematic is the fact that this particular distinction is inherently value laden. In this case, therapeutic engineering brings the subject, in effect to what a human should be, thus begs the question.

In order to avoid 'begging the question' in arriving at the distinction between therapeutic and eugenic engineering, a value-neutral concept of the differences between the two must be devised. One attempt has been to appeal to the notion of natural kinds. If genetic engineering is targeted at remedying a specific pathological condition, such as phenylkutenaria, it is deemed to be therapeutic. However, because pathological disease states are associated with effects, not causes, *inter alia*, there seems to be no 'fact of the matter', only a 'value of the matter'. Disease states are in fact normative because of their perceived effect on the human condition. A simple counterexample can be envisaged, in areas of the world in which malaria is a real threat, individuals who are heterozygous for the sickle-cell trait are at a definite advantage, whereas in all other areas, this genetic makeup is disadvantageous, thus, at least for some conditions, there is no categorisation as disease possible. What is more, there is no exemplar pathological state that takes in all possible

subjects of therapeutic engineering, therefore an appeal to natural kinds cannot provide the necessary basis for a clean distinction[2].

An approach similar in nature to that of using natural kinds is to view the biological function of components of the human body. Thus the biological function of the heart is to pump blood throughout the body, any condition that reduces the ability of the heart to perform its role can be viewed as a target for therapeutic engineering. However, even this seemingly disambiguated example poses a problem. How is the suitable target level of function determined? If the average human heart is capable of beating at 180 bpm for short periods, and marathon runners' hearts are capable of beating at 240 bpm for the same duration, to what level should a deficient heart, which may only achieve 80 bpm without genetic intervention, be raised? Again, a value laden context is evident. Sickle-cell anaemia can once again be used to show that biological function is not necessarily a value-neutral framework for differentiation between therapeutic and eugenic. The biological function of the circulatory system in general, and the red blood cells specifically, is to transport oxygen from the lungs to the body tissue, individuals heterozygous for the sickle-cell trait have inferior circulatory systems to individuals without this trait, thus a functional argument would dictate therapeutic intervention, but again, in areas in which malaria is endemic, the biological function of the circulatory system plays second fiddle to the ability of the heterozygous individual to combat infection. The undeniable (primary?) biological function of males is to inseminate females of the same species. Does this then condemn homosexuals to pre-genetic engineering history. The use of biological function as yardstick for therapy appears to render this conclusion inescapable. It would seem, however, that the predispositions and projects of rational moral agents should not be subject to such an arbiter of value, and that there is no option but to dispense with biological function as a candidate.

The intuitive difference between therapeutic and eugenic engineering, in a sense, can be viewed as the difference between necessary and unnecessary. Examples of unnecessary, nay wicked, genetic engineering often include the changing of progeny's eye, skin, and hair colour to suit the majority of the social context. While these would appear *bona fide* examples of 'cases that ought not be allowed' two observations can be made. First, while these specific examples may be unnecessary now, what if in two hundred years time the ozone layer was so depleted that blue eyes and fair skin were so disadvantageous as to

[2] Tony <Insert Surname here>'s talk on natural kinds and the distinction between therapeutic and eugenic engineering.

increase the likelihood of carcinoma tenfold, in that context, the 'unnecessary' becomes vital. The flip-side also exhibits an unwillingness to be compartmentalised into therapeutic and eugenic, as in the case of sickle-cell anaemia. Second, an implicit assumption made by those who fear genetic engineering is that allowing such arbitrary whims will inevitably lead to a homogenisation of humanity. The argument would run as follows. If all forms of genetic engineering are allowed, at the discretion of some person (parents) or institution (state), then that agent, following utilitarian theory, seeking to maximise a specific store (e.g. happiness), will drive humans towards being identical.

Before this point is addressed, however, it would be prudent to backtrack somewhat. It has been shown that there is no value-neutral means of distinguishing therapeutic from eugenic engineering, thus the question of whether and how any form of genetic engineering is permissible, or even obligatory, must be answered. There are three issues in this case. First, whether genetic engineering of any form is permissible. Second, who decides on the specific changes to be made in an individual. Third, whether the aforementioned 'fear' bears blanket justification, whether it requires qualification, or whether it is the output of closed minds.

The engineering of humans dates back long before the advent of modern genetic techniques. It is considered the right of parents to shape the environment in which their offspring are raised, with minimal rights of intervention by the state, and only in extreme cases. It must be assumed that strong genetic determinism is a fad of the past, and that the environment affects the shaping of young humans as equally as their genetic composition. Only extreme cases of parental social engineering, such as 'hot-housing' are frowned upon. A ban on genetic techniques to mould progeny into what parents see as fit is sanctimonious to say the least. Liberal eugenics dictates that the choice lies with the parents. This is consistent with views about 'normal' methods of raising children. The role of the state is confined to an informational role. The intervention of the state in parental affairs should only be permissible when the downstream effects of a particular decision of the parents has gross negative effects on either the child or on society. A liberal society allows personal freedom, but this should not be mistaken as a green light to impinge on the rights of other members of the society. While the picture of liberal eugenics has been depicted as rosy, it must be noted that there are currently no societies in which such a framework could operate properly.

It must be accepted that genetic engineering, in general, is morally permissible. Having adopted a utilitarian framework, it must be put to the test. A moral obligation or

permission is only valid in cases in which a decision between different courses of action can be made. It is assumed from hereon, for the sake of argument, that genetic techniques bear no cost of failure, that is, the technology is sufficiently robust that a decision to undergo a procedure will result in success. In the utilitarian framework this restriction can be relaxed by calculating courses of action in a decision theoretic manner. Take, for example, a wealthy couple, who are informed that their child will suffer from phenylkutenaria. Their options are to abort, to undergo gene therapy to remedy the deficiency, or to provide support for their child through strict dietary regimes. Since all three options are obtainable, the moral obligation of the parents is to choose the course of action which will produce the greatest benefit. Since there is no possibility of failure for the genetic intervention, it would seem that this course of action is in fact obligatory.

A less emotive, but equally useful, example can be envisaged. A potential child has been diagnosed as myopic, the choice in this case is between genetic intervention to prevent the myopia, provision of corrective lenses for the child until it can provide for itself, or do nothing. In western society, the provision of corrective lenses is almost morally obligatory. Children can not learn as well without in school, and people requiring corrective lenses may not drive without. While few would argue that quality of life is severely restricted by the need for corrective lenses, a comparison can be made between those that require lenses and those that do not. If, at any point during the lifetime of a myopic individual, they lost or broke their glasses/contacts, then in comparison with an individual who did not require lenses, they would have been less happy, *ceteris paribus*. Perhaps an individual feels more comfortable wearing glasses. If this is the case, and it is clearly not one of familiarity, then they are free to wear glasses with plain lenses if they wish, what the genetic intervention allows is the ability of the offspring to make an unfettered decision about their own life, instead of being (possibly) restricted as they would have been without genetic intervention.

These cases have dealt with issues which would be described as therapeutic, even though that term has been left behind. What of choices made by parents which provide no such benefit, but are merely at their whim, such as the decision of African-American parents to have children with Caucasian physical traits. All that can be said about this is that without allowing it, there is not much evidence to believe this would happen. Most people are proud of their heritage, and would not make such decisions. What of the argument that allowing genetic engineering would homogenise the human race? The best response is that no single

‘type’ is the best, just as there are different environments, there are different optimum genotypes for each environment, as is evidenced in nature.

It has been shown that a clear distinction between therapeutic and eugenic engineering can not be made. Moreover, the only ethical theory which deals adequately with future humans suggests that in some cases genetic engineering is not only permissible, but also obligatory. There is no sufficient distinction between genetic engineering and environmental engineering to allow a ban of one and the permission of another. Since genetic engineering has been around for a hair’s breadth in the scope of humanity, it is not surprising that there is emotive opposition, often fuelled by religion and misunderstanding. As the overall understanding of the human genome, and the intricate webs of connections of which genes are a part improves, the genetic debate of the twentieth century may be shelved with the Salem witch trials in the library of human error.