

Medical Ethics

Eugenics

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“The wisest thing in the world is to cry out before you are hurt. It is no good to cry out after you are hurt; especially after you are mortally hurt. People talk about the impatience of the populace; but sound historians know that most tyrannies have been possible because men moved too late. It is often essential to resist a tyranny before it exists. It is no answer to say, with a distant optimism, that the scheme is only in the air. A blow from a hatchet can only be parried while it is in the air.”

So G.K. Chesterton begins his book *Eugenics and Other Evils*.¹ This work was written in the early decades of the twentieth century and articulates Chesterton’s concerns regarding the nascent science of eugenics. At this point in history all that is proposed is selective breeding. Chesterton offers the following definition.

“Eugenics, as discussed, evidently means the control of some men over the marriage and unmarried of others; and probably means the control of the few over the marriage and unmarried of the many.”

Chesterton did not look further forward to imagine what possibilities scientific advances might bring to this endeavour and may not have anticipated how swiftly this particular axe might fall. Not many years later, Aldous Huxley would publish his *Brave New World*.² The story opens with a description of the workings of the Central London Hatchery and Conditioning Centre where the next generation of genetically determined embryos are incubating. Whilst Huxley had an impressive imagination, he did not foresee how rapidly things would change. He had set his story hundreds of years in the future but in his reflections on the tale in *Brave New World Revisited*,³ he laments the speed at which his predictions were being fulfilled. However, even then, the scientific advances that would facilitate the Central London Hatchery were still the stuff of science fiction and science fiction has continued to riff on the themes afforded by genetic testing and genetic manipulation. For example, the film *Gattaca*⁴ portrays a not too distant future where genetic testing of new-borns is routine and those who do not come up to expectations are deemed to be “invalid”. This status blights the individual’s future – why invest time and effort training someone who has less potential than their peers? Such discrimination is, of course, illegal, but laws can be worked around and the film follows one man’s attempt to live beyond discrimination based on his perceived genetic potential. *Blade Runner*⁵ and its sequel *Blade Runner*

*2049*⁶ are set in a dystopian future where extreme genetic manipulation facilitates the creation of human replicants – biological beings like humans (and often with superior intelligence and strength) but significantly not humans – who serve as slaves. It may be easy to dismiss such films as pure fantasy but, like Huxley, we may be surprised at the pace of change.

Let us start with genetic screening. It is part of NHS England’s Long Term Plan to be the first national health care system to offer whole genome sequencing as part of routine care. The target is to sequence 500,000 whole genomes by 2023/24. Initially this will be targeted but the debate has begun regarding the appropriateness of its use in untargeted screening of newborns or in the antenatal period.^{7,8}

You may recall from years ago being told about the Wilson and Junger criteria for screening, as adopted by the World Health Organisation.⁹

The second criteria states that there should be a treatment for the condition and the eighth there should be an agreed policy on whom to treat. One of the problems raised by such screening is the discovery of disease for which there are no current therapies and the identification of risk factors for poor health. With regard to serious conditions for which there is no cure, it is sobering to reflect on the current state of play with existing antenatal screening. For example, in the UK following a diagnosis of Down syndrome, 90% of pregnancies are terminated;¹⁰ in Iceland the figure is closer to 100%. With regard to identification of risk factors, it is not hard to imagine the insurance industry wishing to utilise such data – perhaps initially with encouragement of lower premiums for those willing to provide evidence of a favourable genetic profile voluntarily.

What about gene manipulation? There are broadly two types of gene manipulation; somatic and germ-line. Somatic manipulation affects only the individual patient and is generally deemed to be less controversial. Recent news stories have covered treatments for rare genetic diseases such as leber congenital amaurosis,¹¹ and metachromatic leukodystrophy,¹² and trials are ongoing with treatments for other conditions.¹³ Germline gene editing had previously been considered off limits as any changes would be passed down to succeeding generations but, with the development of CRISPR (clustered regularly interspaced short palindromic repeats) gene editing techniques, it has become technically feasible and, as might be expected, there is an ongoing push



to move the boundaries. In 2015 news reports began to circulate that researchers at China's Sun Yat-sen University had used CRISPR technology to correct the genetic defect that causes beta-thalassaemia. These early stage embryos were not implanted but there was considerable unease that a line had been crossed.^{14,15} However, in 2018 it emerged that the same researchers had edited the genome of embryos in the hope of making them immune to HIV and these embryos had been implanted and carried to term. It is interesting to note that the development of technology often occurs without substantive debate as to whether it should exist. And even if, as in the case of germline gene editing, the prevailing consensus has been that it should not, it only takes a rogue individual to bring the technique into being. One can trace the trajectory of opinion from the initial response that there should be a moratorium on such research to simply questions about safety and governance in the development and utilization of the procedure. The question rapidly changes from *is it moral to pursue this goal* to that of *how should we pursue it?*¹⁶

In *Playing God*,¹⁷ John H Evans describes how the early "thick", substantively rational debates about issues in bioethics, where ends and means were both considered, became "thinner", formally rational deliberations, where the ends are assumed as a given, and the means only are debated. In this story, there is a power-play by the scientists who are uncomfortable with the challenge posed to their assumed jurisdiction over the ethics of experimentation by theologians and philosophers. To prevent direct public scrutiny of the issues, government advisory commissions were formed, and these required a formally rational framework to function. In turn this led to an assumption of an overlapping consensus about the ends of such research and formally rational debate, i.e., deliberation simply about the means. At an early stage the now ubiquitous Georgetown form of Principlism (autonomy, beneficence, non-maleficence, and justice) became the only game in town for the consideration of bioethical issues. Other broader ethical principles, such as the inviolability of human life, were discounted. Evans' structured history provides a helpful context for H Tristram Engelhardt's more personal reflection on these events in *After God*¹⁸. Initially part of the vanguard of bioethics, Engelhardt now sees the discipline as "demoralised and deflated". Another personal view from one inside the debates is that of Leon Kass¹⁹. Whilst Kass, writes as a scientist, the spiritual aspects of the subject are not far from his mind as evidenced by his frequent reference to CS Lewis's *Abolition of Man*.²⁰ Kass also cites Jacques Ellul's *The Technological Society*.²¹ Ellul believed that modern society is dominated by *technique*. Technique is more than simply the application of technology as to achieve an end. Technique is ultimately focused on the concept of efficiency, creating an artificial system which "eliminates or subordinates the natural world." It is easy to see how this fits with the culture of formal rationality adopted by the bioethicists. Whilst Ellul was prepared to some extent to give *technique* as applied to medicine the benefit of the doubt, Postman takes a more skeptical (and

probably more realistic) view.²² New techniques continue to be developed. Recent headlines have informed us of "man-made embryo[s] grown in a lab for the first time" using stem cells from mice. The researchers are quoted as saying that this "opens the door to similar studies with human cells, though there are many regulatory hoops to get through first."²³ In the UK these regulatory hoops come in the form of the Human Fertilisation and Embryology Act 1990. As I write, the Human Fertilisation and Embryology Authority are holding a consultation into the potential revision of the act which would see them granted increased powers; powers that include the licencing of experiments on embryos using germline editing. Much of such debate occurs away from public consciousness and we only hear of the outcomes once the deliberations have ended. To return to the beginning, the axe is in the air and has begun to fall. Should we cry out before it is too late?

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