

4. Is There Anything Special About Genetic Tests? - Genetic Essentialism And Information

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Innovation in medicine almost always creates feelings of moral unease; especially in religiously oriented countries. Evidence to this are technologies such as those of organ transplantation in the 1950s and assisted procreation in the 1970s. Medical Genetics and the investment in the Human Genome Project has created the concern that we may tamper with the very essence of life - our DNA. Whilst on the one hand medicine strives to cure genetic ailments such as Tay Sachs disease, Sickle cell anaemia and Huntington's disease, the prospects of genetics go much further and reach into the realm of enhancement and cloning. Having genetic information at our disposal, can itself affect our very essence by giving us the opportunity to choose who will live or die, and possibly by fostering new eugenic attitudes. But medicine, by its very nature, has always thwarted the natural order. In this light it is appropriate to ask whether there is anything special about genetic tests and whether this follows directly from genetic essentialism.

Genetic Essentialism - a false statement?

Genetic essentialism is the idea that we are our genes, that the nature, or essence, of the human being is in his or her genes.⁽¹⁾ Yet by changing our environment we constantly go against our essential nature. We take folic acid in order to decrease the chance of neural tube defects in babies; we treat all sorts of ailments, including genetic diseases. On a more social level we try to influence our environments by

optimising our chances of survival and competition. We pay money to attend good schools. Parents do their utmost to have the perfect baby. Even contraception is a way of maximising our efforts for those children born into the family. All these environmental factors, let alone the factors over which we have no control, change the outcome which would otherwise result. Thus when it comes to using genetic information to influence the outcome of our babies, some may feel this is a natural responsibility which parents have to carry. Glenn McGee, in his pragmatic analysis of genetics has argued that the attractiveness of genetic intervention is that it allows parents to participate scientifically and systematically in the construction of 'the perfect baby', which all wish to have.⁽²⁾ He exposes this as a natural extension of parent's efforts to participate in the moulding of their offspring, as is education. He warns, however, of the special complexities of reproductive decisions such as expecting too much from a child who was genetically 'chosen' to have a better brain for education or a better body for sport. Parents may put undue pressure on their offspring to satisfy their chosen genetic traits.

But is there a special nature to genetic tests themselves other than defining the moral boundaries in which they may allow us to traverse. It is in the category of 'predictive' and 'pre-symptomatic' testing that most difficult issues arise.⁽³⁾ By pre-symptomatic one implies a belief in the certainty of a positive result; something which is not the case for all 'predictive' testing. In predictive testing the risk of the disorder occurring is reduced but not entirely eliminated. This is probably the case for the Breast Cancer genes BRCA1 and BRCA2. Yet the lack of certainty has certainly induced enough fear in many women to seek radical mastectomies.

Are the Ethical Dilemmas raised by Genetic Information new?

This question has been raised by the British Medical Association in their publication on genetics.⁽⁴⁾ Many of the ethical dilemmas raised in the genetic sphere are the same as for those raised in other areas of medicine and concern confidentiality and acting in the patient's best interests and to avoid harm. The publication argues however that when applied to genetic technology, the usual imperative of maximising benefit and decreasing harm may be seen from a different angle. Our increasing understanding of how an individual's genes can cause or predispose towards a disorder, *widens the scope of decisions to try to bypass or pre-empt nature by terminating pregnancies or by surgical removal of tissues. Moreover genetic choices are more likely to touch the lives of others.* This is the main ethical concern where genetic technology differs from other areas of medicine. The individual's priorities and autonomous choices may not be the sole determinants for performing the tests. Another member of the family may be denied insurance, because a brother, say, had a genetic test in the past.⁽⁵⁾

But how is genetic 'information' different from other medical information in the eyes of insurance, say? Certainly it would constitute discrimination if not all people were asked to undergo genetic testing. But the problem with having all people undergo testing is that they lose their right *not to know* about medical information. A person who has a brother with Huntington's disease may not feel it in his interest to know about the outcome of his future life.

It has been argued that if genetic essentialism is true, then this implies that there is indeed something special about genetic tests, because they tell us something about our very nature. In order to answer whether there is anything special about the nature of genetic tests we must first, therefore, ask

whether genetic essentialism is in fact true, and secondly, whether this directly implies that genetic tests are special. We can thus formulate the questions as follows:

- a. What do we mean by the essence of genetic tests?
- b. Is genetic essentialism a contingent truth, a necessary truth or a falsity?
- c. Are genetic tests special?
- d. Does 'c' depend on 'b'.

Clearly by essence we do not simply mean that DNA is structurally made of nucleic acid molecules. It is the *arrangement* of these molecules into codons which constitutes the *structural reality* of DNA. The essential reality is therefore the information it carries. We can interfere both in the correction of bad mutations and in the inclusion of genes. This choosing indeed interferes with the essential nature of DNA which is to combine randomly as well as by removing a selected amount from the pool of future genes.

Clearly the human individual is not only his or her genetic program. An large number of environmental factors have a role in influencing the outcome of the individual. Whilst the genotype is a specific arrangement of codons, the phenotype it a range of possibilities within which the individual can develop and over which the environment can have a say. To change the limits of the phenotype one needs to change the genotype.

Therefore the problem of essence lies where we want to put our definition: is essence the *range of possibilities* which the environment has on the phenotype, or simply the resultant *status of* the individual, that is one of several outcomes of the phenotype? In other words if my phenotype predisposes me to obesity will my essence in this respect be that of a lean individual if I diet continuously, or that of a lean individual predisposed to growing fat if not careful? It is quite obvious

that the essence of the individual lies not only in what result the environment has had, but in all the range of possible results of different environmental scenarios. This *potentiality-of-being*, so to speak, is in effect the phenotype. It is this phenotype which lasts forever unless in some way the genotype is affected *a priori* (by modification of the germ cells) or *a posteriori* (by modification of the somatic cells). Arguably even these interventions are environmental factors, and the environment continuously effects the genome. Nevertheless it is the genome which ultimately defines the possible phenotypes. In this respect one must conclude that genetic essentialism is true. Moreover one has to conclude that it is thus a natural truth that the genotype affects the phenotype; it is a contingent truth that the environment affects our essence. It can only do so at the whim of the genotype.

We must now ask ourselves whether this makes genetic information special. In other words, is the *predictive* nature of genetic information of relevance to this genetic essentialism? It does not follow that genetic essentialism gives a straightforward claim that genetic information is special. If it does so at all, we must show why.

Let us consider two predictive tests, the Breast Cancer gene and blood cholesterol, a phenotype test. Clearly the distinction is that the latter is only a phenotype *possibility*. A healthy diet with or without medication may bring cholesterol down and thus reduce my risk of heart disease or stroke. Conversely the BRCA result is there to stay. Research may show that the genetic removal of this gene may or may not have an outcome on phenotype - the appearance of the malignancy. Conversely a change in environment (a mastectomy) will practically eliminate the risk of cancer. So both kinds of tests are affected by a possible environmental solution. But the BRCA result tells the woman something of her essence. It tells the woman she has a definite increased statistical risk of developing breast

cancer. Natural environment will not change this; only intervention would. But the same can be said for cholesterol, since this phenotypic manifestation is also dependent on the genotype.

Therefore one cannot say in this respect that there is anything special about the tests. Even for prenatal diagnosis there are non-genetic tests, such as alpha fetoprotein, that may induce us to eliminate high risk fetuses. Yet the broad aspect of genetic tests gives us a greater potential for not only eliminating affected fetuses, but also for choosing a priori what individuals we want to survive. This *geneticisation* is the main factor pointing to the special nature of genetic tests.

Geneticisation

The 'Cyprus Paradigm' is a clear example of this.⁽⁶⁾ Hoedemakers and ten Have have argued that medical professionals (in Cyprus) do not only consider the burden of a disease on the patient but the future burden of the treatment itself. Paternalism appears in different forms-strategies are used to convey the importance of preventive measures for the prevention of the disease (in this case beta-thalassaemia). This results in social pressures that limits free choice. Responsibility is put on couples as well as on health professionals in reaching their decisions. Quality of life arguments are used to justify remedial actions, such as selective abortion, which became part of general medical practice and acceptable for target groups. This approach was condoned by the World Health Organisation.⁽⁷⁾

Clearly for the large section of the human population who uphold the status of the embryo, this geneticisation plays a crucial role in placing a special status on genetic tests and that this depends on the contingent or natural truth of genetic essentialism.

The 'power' factor

Therefore, the speciality of genetic tests lies in their potential to give us the *power* to choose our offspring. It can extend our medical goals to another 'Race Hygiene'. *But this power is a moral value, rather than a special nature of the test itself.*

There is no way of telling how genetic information used through selective screening of fertilised ova or fetuses will be used. It will invariably involve future generations who were 'made' through such selective processes, and who might in their turn select different traits in their offspring in an effort to avoid those traits which may have rendered their lives a misery.

A significant problem at the root of all this is our comprehension of the status of the embryo. Yet it must be stressed that this is a problem of moral weight on the elimination of 'unfit' potential humans. Of equally significant concern is the pressure which society can put on these selected people and the pressure which these in turn would induce in their offspring. Life would have turned from merely trying to provide your children with a better future and security than you had in your childhood to an induction of, or protection from traits which society has imposed on you, the selected. If giving our children a brighter future means adding to the existent pressure of family size, another pressure of selecting genes, we are removing the liberty in our children to explore their own potentialities. If it can be argued that this does not make genetic information anymore special than other tests, then it could be argued that there is nothing special about genetic information. To pragmatically argue that selecting a child's genetic make-up through information and elimination of other potential children is equivalent to trying to give your child a better education by selecting a better school is being simplistic to say the least. One can only conclude that in today's cultural/scientific ambience, what one does with a test is full of value-laden

choices. It is these choices which render genetic tests special, not their essential nature, nor genetic essentialism.

If, because of the wide-spread use of genetic tests, insurance companies will change the way they work, employers will request tests for safety, and parents will eliminate disabled fetuses and/or choose genetic traits they deem desirable for their offspring, then there is indeed an argument for the special nature of genetic screening and testing.

1. Cranor, C.F. (ed.) *Are Genes US? The social consequences of the New Genetics*, Rutgers University Press, New Brunswick, NJ, 1994

2. McGee, G. *The Perfect Baby A Pragmatic Approach to Genetics*, Rowman & Littlefield, 1997:77-78

3. Harper, P.S., "What do we Mean by Genetic Testing?", in *Genetics, Society and Clinical Practice*, Harper, P.S. and Clarke A.J., Bios Scientific Publishers, 1997:9-10

4. British Medical Association, *Human Genetics*, Oxford University Press, 1998:7-8

5. *Ibid.*, 162

6. see as examples: Hoedemakers, R and ten Have, H., "Geneticisation: The Cyprus paradigm", *Journal of Medicine and Philosophy* 23(3), pp 274-287

7. World Health Organization (WHO) (1983): *Community control of hereditary anaemias: memorandum from a WHO meeting*, *Bulletin of the World Health Organisation*, 61: 63-69.