TREATMENT OF GENETIC DISEASE: WHO IS THE PATIENT?

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Abstract

Genetic research is improving our understanding of the aetiology of disease (including those diseases traditionally not considered to be 'genetic'). Research is also being conducted on personality traits and other variables which have hitherto been considered to be variations of normal. However, gene therapy would allow manipulation of 'normal' as well as 'abnormal' genes. If there are preferences within society for a particular variant of normality, then other variants may be considered as undesirable or even 'abnormal'. Our concept of genetic disease is likely to change.

It has been suggested that the prima facie duty to confidentiality does not apply within genetics, because sharing of genes within families, may mean that information should also be shared. Respect for autonomy may therefore be threatened. It has therefore been suggested

that genetics represents a 'challenge to principlism' within ethics. In addition to tensions between the rights of the individual and the family, there are also tensions with the wider family i.e. society. Various ethical theories are explored that could justify breaking confidences. Unlike other medical settings, the consideration of the *genetic patient* should not be restricted to the individual. I will argue in support of a communitarian approach to health care.

I will contend therefore that the principles of bioethics remain valid. However, a genetic approach offers a new viewpoint on traditional debates such as concepts of health and personal identity.

The title of this paper "Treatment of genetic disease: who is the patient?" contains three elements which will be discussed:

- What is a disease?
- What is a treatment?
- Who is the patient?

What is a disease?

Genetic disease is increasingly being recognised as an important public health issue. This is partly because new technology means that interventions are possible whereas in the past there were none, but also because of the relative rise in genetic disease as a source of morbidity and mortality. In 1900, the infant mortality rate for England and Wales was 154 deaths per 1000 live births, with 4.5/1000 of the total due to genetic disease[1]. By 1980 the infant mortality rate had been reduced to 12/1000. However, the death rate due to genetic disorders remained unaltered. Thus the proportion of infant deaths due to genetic disease has increased from 3 to 40%.

The birth frequency of single-gene and chromosomal disorders is 2% and between 2-3% of couples have a high risk of a recurring condition in their children[2]. However, another consequence of the 'New Genetics' is that the genetic aetiology is being recognised of many diseases not previously included within the domain of medical genetics. For some patients with cancer or heart disease, the strong family history means that a mendelian inheritance pattern can be identified. However, a weaker family history exists for other patients which suggests that they have inherited one or more genes which meant that they were more susceptible to some other etiological environmental or lifestyle factor. A genetic component is now

recognised or suggested for many diseases e.g. breast cancer, bowel cancer, diabetes, schizophrenia, and asthma. In a population survey, Baird et al.[3] found that 5.5% of the population would develop a genetic or part-genetic disorder by the age of 25, and 60% in a lifetime, when common disorders with multiple gene predisposition are included.

Genetic factors have also been suggested for personality or cosmetic traits which have, until now, been considered to be variations of normality e.g. intelligence, aggressiveness, obesity, homosexuality. Discovery of genes controlling such states could potentially lead to demands for gene therapy to modify them. However, interventions of this sort will change the boundaries of disease and normality.

King believed that clinical normality *"is objectively, and properly, to be defined as that which functions in accordance with its design"*[4]. According to Boorse the basic idea behind King's definition *"is that the normal is the natural ... the crucial element in the idea of a biological design is the notion of a natural function"*[5]. Boorse goes on to say:

> Theoretical health now turns out to be strictly analogous to the mechanical condition of an artefact. Despite appearances, "perfect mechanical condition" in, say, a 1965 Volkswagen is a descriptive notion. Such an artefact is in perfect mechanical condition when it conforms in all respect to the designer's detailed specifications... In the case of organisms, of course, the ideal of health must be determined by empirical analysis of the species rather than by the intentions of a designer. But otherwise the parallel seems exact.

Wulff et al. however, criticised Boorse's analogy:

> The first difference between your car and your patient is the obvious one that you possess a manual with the specifications for your patient. What most clinicians do when they receive a laboratory report is, of course, to look up the normal range for the tests in question. They try to solve the problem of the missing specifications by

> resorting to the statistical concept of normality, but often they do not realise the difficulties.[6]

With the exception of a few models of car which have achieved 'vintage status', our expectations of the 'state-of-the-art' car have changed over the years with better performance, appearance and higher specification. In the same way our expectations of human performance have changed, whether it be the ability to run faster, live longer or to have greater intelligence. It is likely that some members of society may wish to use the technology that is available in order to ensure that aspirations are achieved. However, a society comprising of 'idealised clones' may not be desirable, if only because that this would lose an evolutionary advantage resulting from diversity. If we wish to avoid such a 'nightmare scenario' then we will need to place constraints on which states and conditions genetic technology can be used, and hence the ability of the individual to exercise their autonomy.

Within existing medical practice there are examples of the dangers of 'unrestrained' autonomy. Couples are already requesting termination of pregnancy for conditions associated with reasonably normal quality of life. Consider a fetus diagnosed as having cleft lip and palate where there is a small risk (in the order of 1%) of associated tracheo-oesophageal fistula. Following counselling the parents request termination of pregnancy. However, there may be doubts as to the moral justification for this termination. Is it because of the parents do not want a child with cleft lip and palate, even though surgical repair is likely to give a good cosmetic result? If the parents chose termination because of the risk of tracheo-oesophageal fistula, is 1% a sufficiently high risk? As a public health physician I have difficulty in supporting 'unrestrained' autonomy in such circumstances. Such a stance should be reassuring to the geneticists, since improving public health is not dependent on terminating every abnormal fetus. Similar concerns would be raised over termination on the basis of sex (other

than for sex-linked diseases). Thus, maximising reproductive choice, to allow couples to 'create their ideal child', may not always result in valued public health consequences.

What is a genetic disease?

Is there something different about genetic disease, to justify the attention of individuals and committees with an interest in ethics. The Nuffield Council on Bioethics defined genetics disease or disorder as:

> Conditions which are the result of alterations in the genetic make-up of an individual. They may be the direct consequences of defects in single genes (mutations); or in whole chromosomes, parts of which may be lost, duplicated or misplaced; or from the interaction of multiple genes and external factors.[7]

This definition however, is potentially misleading since patients with genetic disease are usually born with their 'alteration'. If the Nuffield Council are suggesting that there is an alteration from some reference standard, who defines this 'ideal genome'? and how do they allow for 'normal variation'? The Norwegian Ministry of Health and Social Affairs stated that:

> The new forms of genetic testing distinguish themselves from other types of medical testing by giving the same result independent of age, independent of medical condition, independent of biological material and independent of the amount of the tested material.[8]

This definition does not encompass all diseases now recognised as being 'wholly or partly genetic', nor does it exclude some that are not considered as 'genetic'. There are two factors that seem to make genetic disease 'ethically special'. Firstly, other family members and future generations are also at risk of developing these disorders, although this criterion also applies to communicable disease. Secondly, there is a perception that our genes are fundamental to

the 'self', and that alterations in the genome whether they be 'natural or man-made' are in some way changing personal identity or the soul itself an act that is traditionally a devine activity. I will return to this later.

What is a treatment?

In the past there was little that could be done for those patients suffering from a genetic disease, other than palliative care. 'Healthy carriers' of abnormal genes rarely found out about their gene status, unless one of their children is a homozygote and develops symptoms of the disease itself. For such 'at risk' couples the reproductive options available to them were to :

- take the risk that future children will be unaffected;
- avoid having children;
- attempt pregnancy with egg or sperm donation;
- proceed with pregnancy, but terminate affected fetuses detected by prenatal diagnosis.

Significant advances in DNA technology have revolutionised clinical genetics and dramatically improved options available to geneticists and their patients. Over the last 25 years there has been an almost five-fold increase in the number of fully identified genetic disorders.[9] This has resulted in improved diagnosis, including the ability to detect carrier states among people with not family history of the disease. There is now the possibility of treatment via gene therapy where an artificial copy of the normal gene is inserted into the genome of patients where the gene has been deleted. The technology will need to solve the problem of inserting the artificial copy of the gene in the correct place in the genome within the appropriate tissue. However, just as 'genetic diseases' could be treated in this way, personality traits may also be manipulated. The report to the Norwegian Parliament stated that:

> ... gene therapy could be used to "improve" humanity, to make Man resistant to special environmental poisons or to improve intelligence or memory. This indicates that it could be difficult to define clear limits between what is considered to be defensible use of gene therapy and that which must be considered dubious or undesirable.[8]

The Report recommended that germline therapy should be banned and that germline therapy should only be applied in cases of serious disease:

> Planned genetic improvement of human beings is not acceptable at any level, except in the case of treating disease in the individual, and that neither through gene technology, nor in any other way must making future generations "better" than those alive today ever be considered.[8]

This statement raises a number of interesting questions: What would count as a 'planned genetic improvement'? Would unplanned alterations be acceptable? What about interventions in pregnancy such as health promotion advice on diet, smoking or alcohol? When the Norwegian report refers to 'future generations' would they draw a distinction between unborn or not conceived? The most important terms which the Report does not define are "better" and "serious". The Norwegians did however question whether a child has the right - and obligation - to inherit its genes from its parents unchanged? But does any patient have a duty to forgo treatment in order to suffer from illness?

Is termination of pregnancy a treatment?

The description of termination of pregnancy as a 'treatment' is controversial. Treatments would normally be expected to result in a prolongation of life and/or an improvement in quality of life. The aborted fetus certainly does not receive an increase in 'quantity' of life and could only be considered to have had an improvement in 'quality' if the baby, when born, would suffer from a disease which meant that quality of life was worse than death. On this basis, if termination is a treatment, the benefits would be accrued by the parents who would not have to care for an affected child nor see him or her suffer. Similarly there will be benefits for any existing siblings who would otherwise have a brother or sister receiving a disproportionate share of the families resources and their parents attention. Termination of an affected fetus may also have benefits for future siblings who would have remained unborn, if the parents had felt that they were unable to support additional children. Indeed there will also be consequences for society, although it has been argued that the presence of handicapped members of society is enriching.[10]

Even before the introduction of gene therapy, and if termination of pregnancy is not classified as a treatment, there are still beneficial interventions that can be offered. For example, counselling assists individuals or couples to come to term with their gene status, and to realise the reproductive options open to them.

Who is the Patient?

What is clear is that the fetus who is suffering from the genetic disease, does not receive the bulk of the benefits of any treatment offered. This is different to the usual situation pertaining in clinical practice where an individual with a disease is described as the patient and receives the majority of the benefits resulting from treatment. Although it should be noted that the relatives of a patient with a non-genetic disease will receive some benefits from successful treatment, for example from reduction in anxiety.

The Oxford English Dictionary defines a 'patient' as an individual with a disease who is receiving treatment.[11] The most important clause of this definition is that the patient is receiving treatment even if this is only in the form of reassurance or palliative care. A person with a disease during its asymptomatic phase, unless identified by screening, will not be receiving health care, and hence should not be called a patient.

In the context of genetic diseases there is scope for extension of the term patient to encompass the family unit on the basis that:

- treatment (be it termination or counselling) may have significant benefits for the whole family;
- other family members will also possess the abnormal gene, although as heterozygotes they will usually be healthy.

Hegel suggested that the individual is subsumed within the family unit:

> The family, as the immediate substantiality of mind, is specifically characterized by love, which is mind's feeling of its own unity. Hence, in a family, one's frame of mind is to have self-consciousness of one's individuality within this unity as the absolute essence of oneself, with the result that one is not an independent person but as a member.[12]

How should we define the family unit? Should it be confined to blood relatives, even though relatives by marriage e.g. husband or wife may have to bare the burden of caring? Does the definition of genetic family be confined to the nuclear family? If the extended family is included, where should the boundaries be placed? However, there are tensions between the interests of individual and their family. For example, to what extent should we consider the interests of a wider family i.e. the rest of society?

According to Hegel *"civil society tears the individual from his family ties, estranges the members of the family from one another, and recognises them as self-subsistent persons ... Thus the individual becomes a son of civil society has as many claims upon him as he as rights against it"*.[12]

Hegel describes the civil society as the *"universal family"* with rights over *"the arbitrary and contingent preferences of parents"*.

Geneticists have accepted the need for involving public health physicians within community genetics to provide "co-ordination and initial evaluation"[13]. Yet geneticists have concerns about what they perceive as the public health perspective. In a study conducted by Wertz and Fletcher[14] in 1988, there was overwhelming agreement that counselling should increase the client's reproductive autonomy. The goals of counselling were seen as helping patients understand their options so that they can make decisions, helping patients cope with genetic

problems, removing or lessening guilt or anxiety and to help patients achieve parenting goals. Many respondents felt that it was important, though not absolutely essential to prevent disease or abnormality. However very few would agree with improving the health and vigour of the population or a reduction in the number of carriers as goals of counselling. For example, Harper writes:

> Should we test all apparently sporadic cases of a disorder such as Alzheimer's disease to detect the minority that are caused by inherited mutations? The response of the public health physicians might depend on the yield of such a test (currently unknown), but of greater importance might be the effect on the family of identifying a serious risk to the mental health of relatives in later life when this was previously unsuspected.[15]

Geneticists seem to perceive public health medicine as an uncaring specialty, making decisions purely on statistics and balance sheets. Public health physicians tend to take a wider, longer term view than other clinicians, and hence will consider the consequences for the population. However, as pointed out by Bentham, "*the community is a fictitious body, composed of the individuals who are considered as constituting as it were its members. The interest of the community then is, what? - the sum of the interests of the several members who compose it.*[16]

Improvement in population health status is achieved by improving the health status of individuals. Hence, childhood immunisation is advocated to protect the individual but also if uptake is high, unimmunised children within the population as a whole, will be protected by herd immunity. There is no conflict between the two objectives. This view has been supported from a philosophical perspective:

> As a matter of logic the goal of a medical genetics service must be connected in some way with the incidence of genetic disease, whether this is expressed in a negative way,

> in terms of a reduction in the incidence of genetic disease, or in a positive way, in terms of promotion of genetic health. The very fact that geneticists think it desirable to offer their service to individuals shows that there is at least a presumption that it is undesirable to suffer from genetic disease and that means should be offered of avoiding it.[17]

Chadwick pointed out *"that autonomous decision-making itself cannot be the only criterion of success"*. Autonomy must also be balanced against the other principles of biomedical ethics: beneficence, nonmaleficence and justice.

The connection between the individual personality and social solidarity was of interest to Durkheim. In his study of "The Division of Labour in Society" he explored *"how does it come about that the individual, whilst becoming more autonomous, depends ever more closely upon society":*

> We believe this is sufficient to answer those who think that they can prove that in social life everything is individual, because society is made up only of individuals. Undoubtedly no other substratum exits. But because individuals form a society, new phenomena occur whose cause is association, and which, reacting upon the consciousness of individuals, for the most part shapes them. This is why, although society is nothing without individuals, each one of them is more a product of society than he is the author.[18]

Various supporters of the communitarian critique have indicated the importance of the community perspective in the moral decisions of the individual. Sandel[19] for example, believed that we must not look to deontological principles of right, but to our own common good. In order to be sustainable, moral principles should be congruous with the values and practices of society in which they are to be applied. Thus when an individual attempts to define their personal moral code they ask 'who am I', 'how am I situated' and 'what is to my benefit' as well as establishing 'what is good for the community', since as Sandel pointed out we *are "partly defined by the communities we inhabit"* and are therefore *"implicated in the purposes*

and ends characteristic of those communities". Liberal theories give priority to the rights of the individual above those of society. They attempt to define an individual out of the social context even though it is the community which nutures and sustains the individual's capacity for autonomous choices.

In Norway, rather than autonomy, respect for human dignity and human rights and the principle of solidarity are stressed.[8] The Norwegians recognise that it is "*necessary to find a balance between protection of integrity of the individual and freedom of choice, and the limit society sets for this choice on the basis of fundamental and overriding values".*

One of the implications of this mentioned in the Norwegian report is that when a fetus is found to be abnormal, society may *"be able to force expectant parents to accept the situation when the parents themselves do not feel able to bear it."* The guidelines to be used when balancing the various interests must be based on a system of values that a great majority in society can accept. However, the Norwegian reject the use of economic analysis "*comparing the costs of prenatal diagnosis against the costs of measures to the benefit, and care of, the disabled".* In addition families who have a disabled child would continue to have the same right to receive support from society, whether or not the defect was detected by prenatal diagnosis.

A threat to confidentiality?

One of the ways that an individual may exercise their autonomy is by choosing to request confidentiality. The Hippocratic Oath contains the phrase *"whatever, in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which*

ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret".[20]

Within the United Kingdom, The General Medical Council's Code of Professional Conduct stipulates that:

> Patients are entitled to expect that the information about themselves or others which a doctor learns during the course of a medical consultation, investigation or treatment, will remain confidential. Doctors therefore have a duty not to disclose to any third party information about an individual that they have learned in their professional capacity, directly from a patient or indirectly, except" when disclosure is "required by statute", "in the public interest", or "in connection with judicial proceedings".[21] (para. 76, 85, 86 and 87).

However, the GMC recognises that:

> Special problems relating to confidentiality can arise where doctors have responsibilities not only to patients but also to third parties as, for example, where a doctor assesses a patient for an employer or an insurance company. In such circumstances, the doctor should ensure that at the outset patients understand the purpose of any consultation or examination, are aware of the doctor's obligation to the employer or insurance company and consent to be seen by the doctor on those terms. Doctors should undertake assessments for insurance, or of an employee's fitness to work, only where the patient has given written consent.[21] (para. 90).

A particular category of interested third parties are other family members who either may have an obligation to care for their 'loved ones' with a genetic disease, or may themselves be at risk of carrying an abnormal gene or of developing the genetic disorder themselves. The Report of the Committee on the Ethics of Gene Therapy (Clothier Report) stated that:

> The duty of confidentiality is by no means absolute; it is balanced by a duty of disclosure. The tension is heightened when the special qualities of genes and genetic events give rise to different, and possibly conflicting, interests of kindred, including those yet unborn, who share, or might share, the same genes. For example, an

> individual might be the source of genetic information which is important to relatives. It might be important to their health care, decisions on parenthood, or life plans which might be influenced by known health risks ... These factors have a bearing on the confidentiality of such information and the circumstances in which it might be disclosed. [22] (para. 4.15).

A report on 'Ethical issues in clinical genetics' published by the Royal College of Physician of the UK also suggested that developments in genetics could alter the balance of weight given to the principles of biomedical ethics:

> Because of the nature of genes, it may be argued that genetic information about any individual should not be regarded as personal to that individual, but as the common property of other people who may share those genes, and who need the information in order to find out their own genetic constitution. If so, an individual's prima facie right to confidentiality and privacy might be regarded as overridden by the rights of others to have access to information about themselves, rather as rights to privacy in the home presumably do not extend to denying access to other people whose property is being held on the premises.[23] (para. 4.10).

Very little explanation is given within these reports of the ethical theories and principles underpinning these recommendations. The Nuffield Council Report on Bioethics supported a prima facie duty of confidentiality although they adopted the view that "a person acting responsibly would normally wish to communicate important genetic information to other family members who may have an interest in that information" [7] (para. 5.25). It suggests that counsellors should encourage the counsellee to allow release of information:

> The best way of ensuring that genetic information is appropriately shared with family members (and occasionally with other third parties) is through the information and counselling procedures... the desirability of sharing information with family members can be emphasised.[7] (para. 5.28).

There are analogies here with Kant's Categorical Imperative[24]:

> Act as if the maxim of your action were to become through your will a universal law of nature.... Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end... So act as if you were through your maxims a law-making member of a kingdom of ends.

Thus, it could be suggested to the counsellee that they should consider if they would wish to be given information obtained from a relative that would affect reproductive decisions. however, the positions taken in these various reports are usually consequentialist in nature. For example, the British Medical Association have stated that:

> doctors must respect confidential information about individuals, but should they withhold information from people who can benefit medically from it. These questions can only be defined in terms of the individual, the group and society. Certainty about an individual's genotype might affect his attitudes to life, and society's attitudes to him, with the possibility of considerable medical, economic and social repercussions. The importance of such information probably outweighs the importance of complete individual medical confidentiality ... [25] (para. 5.14 and 5.15).

The Nuffield Council Report suggested that:

> there would be a stronger case for overriding individuals' objections where the information would influence a decision having potentially damaging rather than merely inconvenient consequences for other family members.[7] (para. 5.31).

Here there are also echoes of John Stuart Mill in his essay "On Liberty". Mill argued that freedom means:

> doing as we like, subject to such consequences as may follow: without impediment from our fellow creatures, so long as what we do does not harm them" nor "attempt to deprive others of theirs, or impede their efforts to obtain it.[26]

The balancing of rights and duties has been enshrined in a number of states on human rights. For example the United Nations Universal Declaration of Human Rights indicates that the

exercise of a person's rights and freedoms my be restricted for the purpose of meeting the *"just requirements of morality, public order and general welfare in a democratic society".*[27] Similarly the European Convention on Human Rights states that:

> there shall be no interference by a public authority with the exercise of this right [to respect for private and family life, home and correspondence] except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health and morals, or for the protection of the rights and freedoms of others.[28]

Thus social control over an individual's reproductive autonomy may be legitimate if it is necessary to prevent harm to other individuals. For example, prejudice that may be experienced by individuals who are reclassified as being 'abnormal'. In addition, there are special situations where society should be paternalistic by intervening in the exercise of autonomy. For example, in the context of the genetic testing of children or the mentally incompetent. John Stuart Mill believed that: *"there is no one so fit to conduct business, or to determine how or by whom it shall be conducted, as those who are personally interested in it"*[26]. Thus, in most situations a utilitarian would accept the judgement of the individual as to which course of action is in their own best interests. However, children are usually not considered legally or morally competent to make such judgements. Parents will usually make decisions on behalf of the child. There may however, be situations where parents may treat their children as 'means' rather than 'ends'. For example, as part of genetic linkage studies it may be necessary to collect genetic information from a number of family members, some of whom may be children, in order to establish a diagnosis.

The special right of access to personal confidential information by other family members depends in part on an emotional sense of duty, but is mainly a consequence of membership of a common gene pool:

> Prima facie rights to confidentiality may also be overridden in genetics by considerations of a quite different kind, having to do with the fact that genes are shared by members of a family.[23] (para. 4.8).

It has been suggested that the particular problems in the use of the principles of biomedical ethics (as defined by Beauchamp and Childress[29]) within the context of genetics, actually represents a challenge to 'principlism'. Green[30], for example, has argued that the four principles are not sufficiently grounded theoretically, while Wertz and Fletcher[31] have proposed that some other set of principles should be used derived from the perspective of the ethics of care. However, Beauchamp and Childress' principles remain valid, all that is required is a proper weighing of their relative merits, rather than assuming the preminace of autonomy.

Beauchamp and Childress themselves recognised that as with all moral principles, the principle of autonomy *"has only prima facie standing"*. They go on to say that:

> it is always an open question which restrictions may rightfully be placed on choices by .. subjects when these conflict with other values. If choices endanger the public health, ... it may be justifiable to restrict exercises of autonomy severely. The justification ... being some competing moral principle such as beneficence or justice.[29]

Did Aristotle discover DNA?

One implication of such arguments may be that a genetic approach could throw new light on philosophical debates. Philosophers writing before Aristotle, for example Plato, had depicted

the soul as an 'unwilling prisoner in the body'[32]. However, in *De Anima*[33], Aristotle described the soul as the natural and appropriate controller of the body and indeed used the body to carry out its various activities:

> It is not that the body is the actuality of the soul but that the soul is the actuality of some body. And for this reason they have supposed well who have believed that the soul is neither without body nor a kind of body. For it is not a body but belongs to a body, and for this reason is present in a body and a body of the appropriate kind

Aristotle sometimes thinks of the soul as a set of capacities: nutrition, sense perception, intellect, motivation (movement):

> The soul is the source of the functions above enumerated and is determined by them .. But whether each one of these is a soul or part of a soul and, if a part, whether it is only distinct in account or separable in space also, is a question the answer to which is in cases not hard to see: other cases present difficulties. For just as in the case of plants some of them are found to live when divided and separated from each other (which implies that the soul in each plant, though actually one, is potentially several souls), so, too, when insects are cut up, we see the same thing happen with other varieties of soul: I mean, each of these parts has sense perception and moves from place to place, and, if it has sense perception, it has also imagination and desire.

To later writers (the most notable of which being Descartes) the inclusion of nutrition within the capacities of the soul seemed incongruous. However, as Lawson-Tancred pointed out, Aristotle's account of the soul was:

> an exercise in what might be called Meta-biology. That is to say, it seeks to give a coherent conceptual framework within which the phenomena of life can be most comprehensively, economically and adequately explained.[33]

Jeremy Campbell has highlighted the regard held for Aristotle among molecular biologists[34]. He quoted a remark of Max Delbrueck, a professor at the California Institute of Technology, who suggested that "if the Nobel committee were able to award the prize for biology

posthumously, they should consider giving it to Aristotle for the discovery of the principle of DNA".[35]

Aristotle's thinking was different from the materialist and mechanical explanation of nature that had been traditional. He was more concerned with the way in which things come into being, change, and pass away, whether these be plants and animals or earth, air, wind, fire and water. In Aristotle's thinking, change does not occur by random chance but rather because 'things' posses a kind of concept, or plan, which they endeavour to realise, each in its own way. A chicken fulfils the plan implicit in the egg, an oak tree the "concept" contained in the acorn. The blueprint which the chicken and the oak tree use is contained within their genome. Thus if Aristotle had be writing in modern times he may have concluded that the genome is the location for the soul. With the gene in mind, Aristotle's suggestion that a plant possesses a soul does not seem so absurd, since plants contain D.N.A.. Similarly Descartes exclusion of bodily functions from his description of the soul seems unnecessarily restrictive, and Aristotle's wider analysis may be more appropriate.

Personal identity

If one or more individuals share genes then do they also share aspects of soul? I raise the question more as a point for discussion than as a serious conclusion. However, a genetic perspective may also offer a new direction to the discussion on personal identity. While it is likely to be difficult to sustain an argument for co-ownership of soul, a number of authors have described the implications of a divided brain being transplanted into different bodies. Again I do not propose to take this line of argument very far, but consider the following problem raised by Parfit:

> My body is fatally injured, as are the brains of my two brothers. My brain is divided, and each half is successfully transplanted into the body of one of my brothers. Each of the resulting people believes that he is me, seems to remember living my life, has my character, and is in every other way psychologically continuous with me. And he has a body that is very like mine.[36]

He goes on to ask: *" What happens to me? There are only four possibilities: (1) I do not survive; (2) I survive as one of the two people; (3) I survive as the other; (4) I survive as both."* Parfit correctly rejects the first of these possibilities since in theory (although at present not technically possible) he could survive if his brain was successfully transplanted and people can survive with half of their brain destroyed. Parfit also had difficulties with the next two possibilities. Assuming that each half of the brain is similar and so to start with each person is similar, how can he only survive as one of the two people, and what makes him one rather than the other?

Parfit concedes that one interpretation is that he survives as a divided mind and one body. There is an analogy here with Nagel's description of one body with a divided mind[37], that can be created by an operation used in the past to treat epilepsy which involved the division of the corpus callosum. However, Parfit concluded that:

> if a mind were permanently divided, and its halves developed in different ways, it would become less plausible to claim that the case involves only one person... Suppose we admit that the two 'products' are, as they seem to be, two different people. Could we still claim that I survive as both?... But it is hard to think of two people as, together, being a third person.

Yet, in the context of genetic reproduction this is our usual way of thinking. Except that rather than division of a brain, reproduction involves division of the genome. The difficulty here is that to begin with there were two people rather than one. In order for the argument to

be of any use, it requires imagining the creation of an new 'individual' when a couple form a relationship. A consideration of genetics could also assist Parfit with other difficulties that he had.

> A future person will be me if and only if this person is both living and has more than half my brain ... It is an intrinsic feature of this relation that it can take only a one-one form. It is logically impossible for two future people both to have more than half my brain.

However, random inheritance of half the parental gene pool means that the probability of two siblings having virtually all genes in common is high. Of the estimated 100,000 genes within the human genome, 99% are common to all humans. Individual diversity is a result of variation in the remaining 1%. There is a 50% chance of two siblings both inheriting a particular gene from a parent The difficulty that various writers have had with simultaneous existence of two or more individuals with the same personal identity is not an issue if genes are the only determinants. Since this would be the case with identical twins. Whilst psychological continuity would not be maintained after birth, it is probable that two close family members would have many memories and experiences in common.

While such arguments may seem contrived, they do offer further justification for different rules to apply for confidentiality within genetics. If the right to autonomy arises from the possession of a soul or a personal identity which are shared in part with family members, then these relatives may also have an interest in the exercise of that autonomy, in proportion to the percentage of genes shared. On this basis, since all the members of the gene pool will have many common genes, then this will also support societal intervention depending on the balance of interests.

Conclusion

In conclusion therefore, I not believe that genetics represents a *"challenge to principlism"*. There is justification to revisit traditional debates. For example, our concept of health is likely to change. It may already be too late to prevent research into the genetic basis of personality traits, and in any case moratoria may be ineffective. Genetics also provides support for an Aristotelian interpretation of personal identity. While the principles of biomedical ethics will remain intact, genetics may encourage a shift away from the primacy of autonomy back to a more balanced weighting as laid out in the Hippocratic Oath, with a move from libertarianism towards communitarianism.

Bibliography

1. Connor JM. Genetic Aspects of Prenatal Diagnosis. *J Inherited Metab Dis* 1989; 12 (suppl 1): 89-96.

2. Working group of the Clinical genetics Committee of the Royal College of Physicians. *Purchasers' Guidelines to Genetics Services*. London: Royal College of Physicians of London, 1991.

3. Baird PA, Anderson TW, Newcombe HB, Lowry RB. Genetic disorders in children and young adults: a population study. *Am J Hum Genet*, 1988; 42: 677-93.

4. King CD. The Meaning of Normal. *Yale Journal of Biology and Medicine* 1945; 17: 493-4.

5. Boorse C. On the Distinction between Disease and Illness. In: Caplan AL, Engelhart HT, McCartney JJ (Eds.). *Concepts of Health and Disease*. Reading (Massachusetts): Addison-Wesley Publishing Company, 1981: 545-77.

6. Wulff HR, Pedersen SA, Rosenberg R. *Philosophy of Medicine*. Oxford: Blackwell Scientific Publications, 1990.

7. Nuffield Council on Bioethics. *Genetic Screening Ethical Issues*. London: Nuffield Council on Bioethics, 1993.

8. Ministry of Health and Social Affairs - Norway. *Biotechnology related to Human Beings Report No.25 (1992-3) to the Storting*. Oslo: Ministry of Health and Social Affairs, 1993.

9. Mckusick VA. *Mendelian Inheritance in Man*. 9th ed. Baltimore and London: The John Hopkins University Press, 1990.

10. Perske R. *Circles of Friends: People with disabilities and their friends enrich the lives of one another*. Nashvile: Abingdon Press, 1992.

11. *Shorter Oxford English Dictionary*. Oxford: Claredon Press, 1973.

12. Hegel G. *Philosophy of Right*. Knox TM (trans.). London: Oxford University Press, 1967.

13. Harper PS. Genetics services in the community. *J Med Genet* 1990;27:473-474.

14. Wertz DC, Fletcher JC. Attitudes of Genetic Counsellors: a Multinational Survey. *American Journal of Genetics* 1988; 42: 592-600.

15. Harper PS. Genetics and public health. *BMJ* 1992; 304:721.

16. Bentham J. *An Introduction to the Principles of Morals and Legislation* (edited by Burns JH, Hart HLA). London: The Athlone Press, 1970: 12.

17. Chadwick R. What counts as a successful outcome of genetic screening? *J Med Ethics* 1993; 19: 43-46.

18. Durkheim E. *The Division of Labour in Society.* Halls WD (trans.). Basinstoke (UK): Macmillan Press, 1984.

19. Sandel M. The Political Theory of the Procedual Republic. Revue de Metaphysique et de Morale, 1988; 93: 57-68. Quoted by Kukathas C and Pettit P. *Rawls: A Theory of Justice and its Critics.* Cambridge, Polity Press, 1990.

20. Hippocratic Oath. In: British Medical Association. *Medical Ethics Today*: Its Practice and Philosophy. London: BMA, 1993: 326

21. General Medical Council. *Professional Conduct and Discipline: Fitness to Practise.* London: General Medical Council, 1992.

22. *Report of the Committee on the Ethics of Gene Therapy (Clothier Report).* London: HMSO, 1992. Cm 1788.

23. Kant I. *Groundwork of the Metaphysic of Morals.* In: Paton HJ (trans.). *The Moral Law.* London: Hutchinson University Library, 1948.

24. British Medical Association. *The Handbook of Medical Ethics.* London: BMA, 1980: 30.

25. Mill JS. *On Liberty.* In: Gray J. *On Liberty and Other Essays.* Oxford: Oxford University Press, 1991.

26. United Nations. United Nations Universal Declararion of Human Rights (1948, article 29) In: Council of Europe. *Human rights in International Law: Basic texts.* Strasbourg: Council of Europe Press, 1992.

27. Council of Europe. Convention for the Protection of Human Rights and Fundamental Freedoms, (1950, article 8). In: Council of Europe. *Human rights in Internatal Law: Basic texts.* Strasbourg: Council of Europe Press, 1992.

28. Working group of the Royal College of Physicians Committees on Ethical Issues in Medicine and Clinical Genetics. *Ethical Issues in Clinical Genetics*. London: RCP, 1991.

29. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* (3rd Ed.). New York: Oxford University Press, 1989.

30. Green R. Method in bioethics: a troubled assessment. *Journal of Medicine and Philosophy* 1990; 15: 179-197.

31. Wertz DC, Fletcher JC. Privacy and disclosure in medical genetics examined in an ethics of care. *Bioethics* 1991; 5: 212-232.

32. Plato. *Phaedo*. Gallop D (trans.). Oxford: Oxford University Press, 1993.

33. Aristotle. *De Anima*. Lawson-Tancred H (trans.). London: Penguin, 1986.

34. Campbell J. *Grammatical Man: Information, entropy, language and life.* London: Allan Lane, 1983.

35. Delbrueck M. How Aristotle Discovered DNA. In: Kerson Huand (ed.). *Physics and our World: a symposium in honor of Victor F Weisskopf.* New York, American Institute of Physics, 1976.

36. Parfit D. *Reasons and Persons*. Oxford: Claredon Press, 1984.

37. Nagel T. Brain Bisection and the Unity of Conciousness. Perry J (Ed.). *Personal Identity*. Berkeley: University of California Press, 1975: 227-245.