Genetic Engineering: Creating an Ethical Framework

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Abstract: Biotechnology, genetic engineering, genetic technology, gene splicing, recombinant genetics, embryonic and adult stem cell research are some of the familiar themes and topics in contemporary daily media releases. This essay seeks to highlight some of the recent developments in biotechnology, their implications and relevance for society, for ethics, and for contemporary theology. While recognising the work in this field on a global level, this essay will look at some Australian contributions to this debate. Some key ethico-legal questions are posed in formulating an ethical framework for genetic engineering to which the insights of theology can make a positive contribution.

Key Words: bioethics; genetic engineering; Human Genome Project; genetic therapy; genetic screening; biological warfare; genetic intervention; cloning; legal ethics of genetics

The science of genetic engineering has progressed to a point where we can definitively state that such manipulation will shape the society of the future. As the number of genetic interventions already possible increases, the ethical application of each should be examined. Christian theological ethics, in proclaiming the dignity and the rights of each human person, should endeavour to understand the complexities of these emerging sciences. The use of genetic engineering and manipulation needs to operate from an ethical framework with the benefits of this technology being weighed up against possible harmful effects. Though the responsible monitoring by governments, legislators, and scientific organisations is seen as essential, it equally is the responsibility of each competent individual to be morally aware when confronted with issues related to this new technology; this then enters into the domain of ongoing moral, ethical and theological education.

The current and potential impact of rapid developments in biotechnology to effect new innovations in medicine and drug development, as well as such diverse areas as crime detection, agriculture, pollution control and industrial processes, brings into question how these techniques can be used constructively without damaging the cornerstone of Christian ethics, namely respect for human life.

Genetic engineering has arguably raised the most important and controversial ethical issues within the past decade. It represents a technical endeavour that has the potential to change human life as we understand it. The purpose of this paper is not to delve into the technical details of genetic manipulation; however, a brief explanation may be instructive. The basis for human life (and life in general) is encoded in a molecule called $deoxyribonucleic\ acid\ or\ DNA$. The human DNA contains $3\times10^{12}\ nucleotide\ bases\ which$

are arranged in precise sequences. Groupings of nucleotide bases constitute genes and there are thought to be 30,000 - 50,000 genes present in the human genome. Genes code for the production of certain proteins and physical characteristics. If a base sequence is damaged, mutated or otherwise changed, a wrong code results. This can lead to abnormal proteins and abnormal characteristics being produced (*Human Genome Project 2003*).

Our current scientific understanding suggests that genetic intervention may allow the faulty genes to be removed and the correct ones to be inserted, resulting in the normal expression of the genes, and thus the elimination of the abnormal conditions. The adult human body is estimated to consist of 10^{20} body cells or somatic cells. In addition, the ova or sperm cells, known as germ cells, allow for the reproduction of the species. Genetic manipulation can be applied to either of the somatic or germ line cells. This in itself raises ethical questions for it can be argued that any changes made to *somatic cells* are restricted to one individual, whereas changes to *germline cells* have the potential to be passed onto future generations and thus may have effects on the whole of humanity as an evolving species.

It may be argued that genetic engineering, as a science, is ethically and morally neutral except in the intentions and consequences attributed by its artisans. In other words, depending on the application of this technology, and on the actual outcomes of such use, some utilitarian conclusions can be drawn about the morality of such applications and outcomes. On the basis of much prima facie evidence, genetic manipulation has the potential to provide positive benefits such as the alleviation of pain and suffering, the improvement in the quality of human life in general, and a contribution to the overall well-being of each individual. Nevertheless, counter-arguments can be put that point to the dangers of indiscriminate use of genetic modification as having the potential to do irreparable harm to the individual and society as a whole. At the least, this points to the need for fuller information, education, and exploration about these processes and their outcomes before society embraces this technology. Relevant questions need to be put with regard to the potential medical, sociological and psychological dangers inherent in the use of genetic engineering. Suzuki and Knudtson,² in examining many of these issues in detail, noted that philosophers and ethicists were lagging behind in considering the moral implications of such genetic engineering for the very meaning of contemporary humanity. A range of questions that could give rise to the necessary considerations would include the following:

- (1) Could manipulating a gene to effect a somatic cure for a particular condition cause serious side effects to the patient?
- (2) If genetic manipulation promises to eliminate disease, will all members of society have access to this treatment?
- (3) Is there a possibility that, in the future, some individuals will be conceived with the assistance of genetic technology and, as such, may be positively discriminated for, while those not being conceived in this manner could be regarded as second class citizens?
- (4) Could an individual who receives either germline or somatic cell genetic manipulation suffer psychological problems as a result of the treatment?

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¹ Reiss, M.J. and R. Straughan, *Improving Nature? The Science and Ethics of Genetic Engineering* (Cambridge: Cambridge University Press, 2001).

² Suzuki, D. and P. Knudtson, Genethics: The Ethics of Engineering Life (Sydney: Allen and Unwin, 1989).

- (5) Will information from gene technology be used in the workplace to determine a person's suitability for a particular job?
- (6) What is the implication of the development of legitimate gene therapy as used in the treatment of a disease as an application for nefarious purposes e.g. the applications of genetic technology in warfare?
- (7) If genes can be can be manipulated to produce superior physical attributes, thus allowing for the genesis of a specifically tailored human race, should such knowledge be used to humanity's advantage?
- (8) Just because we have the power and technological ability to facilitate aspects of genetic engineering, should we actually use it and, if so, according to which philosophical, ethical, scientific, and legal guidelines?

As an instance, the genetic technology associated with prenatal screening, human cloning, stem cell experimentation and the possible selection of specific characteristics in human embryos, raise serious ethical and theological questions that need to be addressed. Many of these questions can be addressed through consideration of the *Human Genome Project*.

The Human Genome Project

Much of the information in contemporary genetics is the result of a collaborative international research effort known as the <u>Human Genome Project</u> (HGP). This project is enormous in its ambition to map all of the genes in the human body. This is complex enough when dealing with a single gene let alone 50,000 genes, and this is precisely why the project was always seen as a collaborative one with specific research assigned to individual groups. The end goal of the project is the compilation and correlation of all results to give the genetic picture of the whole human genome.

The HGP had its genesis in the mid-1980s when molecular biologists started to contemplate the mapping of the human genome. Agencies such as the *Department of Energy* and the *National Institutes of Health* in the United States became interested, and finally the U.S. Congress passed legislation to initiate the project in 1987. Since then, due to the massive scale of the task, laboratories around the world participated in the HGP, each laboratory working on a specific designated part of the human genome. The project, the largest scientific collaborative effort in history, is coordinated from Bethesda in the U.S. According to Ralph,³ the aim of the HGP is to "derive the ordered sequence of the 3 billion units" of DNA sequence that spells out exactly what constitutes a physical human being. The benefits are that many human diseases could be treated or even cured if their underlying genetic bases could be determined.

In 1996, Australia was fortunate to have one of its eminent scientists, Professor Grant Sutherland, elected as the President of the Human Genome Organisation the coordinating organisation for the HGP. On 26th June 2000, it was announced that the HGP had realized its goal, culminating in the publication of the first draft of the complete human genome (<u>Human Genome Project 2003</u>).

³ W. Ralph, "The Tale of Life: Mapping Genes and Chromosomes," ECOS 66 (1991): 19.

Gene Therapy

The ethical questions already raised above pose a direct challenge to ensure that knowledge derived from the HGP will lead to proper ethical investigation and appropriate ethical, scientific application where the conditions for human beings can be improved. There already exist some indicative case studies in this regard. For example, sickle-celled anaemia results when abnormal haemoglobin proteins are produced; this is due to a fault in the amino acid sequence of the haemoglobin molecule. In the abnormal protein, the amino acid valine replaces the amino acid glutamic acid, with the inappropriate valine being a result of an error in the nucleotide codon, in the DNA molecule which should be GUANINE-THYMINE-CYTOCINE (GTC) but instead is GUANINE-THYMINE-GUANINE (GTG). This seemingly small error of transcription in turn leads to the abnormal haemoglobin molecule being synthesised. Genetic technology would potentially allow this mistake to be corrected by allowing the incorrect GTG sequence to be replaced with the correct GTC codon, thus ensuring the synthesis of the normal haemoglobin molecule to occur. While this procedure is still experimental, the obvious benefit would be to relieve pain and suffering in individuals afflicted with the sickle-cell condition. It is equally important to realise that this procedure could be extended to a number of genetic conditions.4

Writing from a Catholic perspective, the Australian bioethicist, Elizabeth Hepburn notes that as "co-creators we are called to exercise our intellect in finding solutions to the [physical and psychological] problems we confront and to take responsibility for our actions." For the development and implementation of genetic technology, serious consideration must be given to guiding ethical and scientific principles that would ensure consideration of each individual case. The use of genetic technology must be viewed in terms of the possible advantages and disadvantages that such intervention could bring to the individual and to society.

This individual assessment and approach is preferable to one of simply rejecting or supporting genetic engineering as a whole. Hepburn, however, sensibly urges caution in the use of germ cell therapy as opposed to somatic cell therapy: "Manipulation of the genetic material in somatic cells (ordinary body cells) alters the inherited characteristics in the individual, whereas altering the genetic structure of germ cells (reproductive cells) changes the characteristics for all subsequent generations."6

The Australian academic and ethicist, Noel Preston equally urges caution: "we can virtually manipulate the genetic structure of individuals but ought we?" 7 From a Christian viewpoint one would argue that the formulation of appropriate theological guidelines would provide a starting point in determining the ethics of employing genetic therapy. Such guidelines would adopt the principle of respect for human life and carefully balance the scientific and therapeutic benefit to the individual against the possible medical, sociological and psychological dangers involved in the procedure.

The Catholic Church has always upheld the integrity, identity, and dignity of the human person as being of primary consideration in formulating a Christian morality. Pope

⁴ G. Kerkut,"Sickle Cell Anemia," http://www.soton.ac.uk/~gk/scifi/sickle.htm, (2003).

⁵ E. Hepburn, Of Life and Death: An Australian Guide to Catholic Bioethics (Blackburn: Dove, Blackburn, Australia 1996), 96.

⁶ Hepburn, Of Life and Death, 90.

⁷ N. Preston, "Ethics and the 21st Century: The Challenge for Educators" (Principals Conference, Brisbane Catholic Education Office, August 19, 1996), 4.

John Paul II in his encyclical, Redemptor Hominis, specifically addresses the demand for ethical and moral guidelines in relation to developing scientific and medical technologies:

The development of technology and the development of contemporary civilization, which is marked by the ascendancy of technology, demand a proportionate development of morals and ethics. For the present, this last development seems unfortunately to be left behind.8

John Paul II furthermore adds that lack of moral and ethical development has led to disquiet concerning "the essential and fundamental question: Does this progress, which has man for its author and promoter, make human life on earth 'more human' in every respect of that life? Does it make it more 'worthy of man'?" There can be no doubt that in various respects it does; however the question recurs about "what is essential: whether in the context of this progress man, as man, is becoming truly better, that is to say more mature spiritually, more aware of the dignity of his humanity, more responsible, more open to others, especially the needlest and weakest, and readier to give and to aid all".10

Miller, in his commentary on Redemptor Hominis, notes that the lack of moral development accompanying technological development is a challenge for the Church.¹¹ If the Church is to remain relevant in the contemporary milieu, it has a need and a duty to develop an ethical viewpoint based not only on its understanding of its own history as part of the moral magisterium, but also as a body cognisant of the sciences which have given birth to such ethical imperatives and questions.

The technical or medical use of genetic engineering must always preserve human dignity, human freedom and the right to the fulfilment of human potential. The elimination or treatment of disease, and the alleviation of human suffering by using genetic interference, are worthy and ethical goals provided that the client is fully informed about any of the possible negative as well as positive consequences of the treatment. A potential negative effect may occur, for example, when a retrovirus that has been rendered harmless is used as a vector to transfer inserted DNA into the patient's cells. There may be a possibility that the retrovirus will have a carcinogenic effect or become infectious and pathogenic. It must be ascertained whether this is an acceptable risk, and a competent client needs to be able to make an informed decision based on a full assessment of any possible risks. These risks can then be balanced against possible therapeutic benefit to the patient.

Hepburn highlights another problem in her concern that "complex behavioural characteristics of humans are governed by groups of genes that need exposure to particular environmental influences in order to be expressed."12 While no specific examples of this problem have been suggested in the literature, one needs nevertheless to be careful that gene therapy does not have any negative behavioural consequences. This may be more of a concern in germ line therapy than in somatic cell therapy; nevertheless all possibilities need to be examined. The role of genes in modifying behaviour is still unclear. Plomin states that "studies of genetically unrelated children adopted early in life into the same family show no more than a chance rate of similarity in personality or

⁸ John Paul II, Redemptor Hominis, Encyclical Letter (1979), §13

⁹ John Paul II, Redemptor Hominis, §13.

¹⁰ John Paul II, Redemptor Hominis, §13.

¹¹ M.J. Miller, ed. *The Encyclicals of John Paul II* (Huntington, Indiana: Our Sunday Visitor 1996), 36.

¹² Hepburn, Of Life and Death, 91.

psychopathology."¹³ This suggests that personality and behaviour are determined to some degree by gene influence. However, scientific evidence for linking our genes to our behaviour is presently not conclusive and we do not have answers to the role of genes in influencing behaviour; thus, caution should be exercised in this respect. We are aware, however, that certain pharmaceutical drugs do affect personality changes and it may be that similar ethical principles have to be applied in specific individual cases. As unique individuals, created for an eternal destiny with a loving Creator, our principal concern should always be for the preservation of our individual humanity and dignity.

Much of the developing science surrounding genetic engineering implies enormous economic and commercial concern. Ethical issues are raised as matters of equity and social justice where considerations for just and proper allocation of resources need to be ensured. In terms of such resource allocation, one needs to consider if the costs of genetic manipulation can be justified in light of more urgent health problems presently not being addressed due to lack of funding. For instance, funding is often not available to ensure sufficient health care in the treatment of acute and chronic heart conditions, in the treatment of various cancers and in providing appropriate palliative care to the terminally ill. Because governments are increasingly concerned that there are more competing interests for a finite amount of funding, it is reasonable to examine cases requiring genetic intervention, and to ensure that resources will be spent where they do the most good. Guidelines are available to medical practitioners to facilitate informed assessment and to prioritise medical cases for which resources should be allocated on the grounds of medical urgency and the quality of life expected as an outcome of the procedure (*National Health and Medical Research Council* (NHMRC) 2003).

Genetic Screening in the Workplace

Advancement in genetic technology has also led to complex problems of social justice where individuals may be denied basic rights due to outcomes in genetic screening. Suzuki and Knudtson point to the ethical implications and morality of genetic screening in the workplace: "information about an individual's genetic constitution ought to be used to inform his or her personal decisions rather than to impose them." ¹⁴ Whether for political, economic or personal use, the use of genetic information could be used in a positive way to screen employees that may be at risk in a polluted workplace. For example, there are genes that predispose some individuals to certain cancers where the risk may be increased in the presence of certain environmental factors. Thus, screening for the relevant marker genes may help an individual use that information to make the decision not to work in a particular environment. Suzuki and Knudtson state that "one might reasonably argue that it is the birthright of every human being not only to dwell in a reasonably unpolluted setting but also to work in one." ¹⁵

The U.S National Catholic Bishops Conference expressed concern about genetic screening in the workplace by citing several hypothetical cases. For example: "Optimum Insurance asks all applicants for individual health care policies to undergo testing for the gene that predisposes to hypertension and Optimum Airlines alerts all its employees that

¹³ R. Plomin, Harvard Mental Health Letter, May 1990, adapted from Brooks-Cole, *Nature and Nuture: An Introduction to Behavioural Genetics*.

¹⁴ Suzuki and Knudston, *Genethics*, 160.

¹⁵ Suzuki and Knudston, Genethics, 175.

testing for sickle-cell trait is now available."¹⁶ Thus, various employer and insurance agencies could infringe on a person's individual decision-making and employment rights just because they may develop a disease which has only a certain probability of occurring, based upon the results of a gene marker test.

Suzuki and Knudtson make the above point well in their citing of US Air Force policy that had once excluded from flight school heterozygous carriers of the sickle-cell gene, fearing that their oxygen-carrying capacity would be poorer at high altitudes. ¹⁷ Since then, no compelling scientific evidence has supported this policy, and it has been abandoned. The point here is that genetics, and science in general, are not infallible - but the economic reality is that companies have already denied insurance policies to individuals who have shown certain negative genetic traits - and these matters are now being decided within the legal system.

Genetics and Biological Weapons

Perhaps one of the more morally clear-cut areas lies in the use of genetics in the development of biological weapons. One only has to witness the world panic caused by the various threats in using a biological weapon such as anthrax. The potential exists for bacterial cells artificially to have new genes inserted into them to enhance their pathenogenicity. Equally frightening is that theoretically an army can be made immune to a specific disease such as anthrax, and consequently allow that same disease to be dispersed into enemy territory. Such scenarios cannot be justified from any religious or socio-political context. As a point of clarification, it also must be noted that biological weapons can be produced without the use of gene technology; however, such technology can greatly increase the efficiency of production of altered pathogens as well as their virulence. Nevertheless, the use of biological weapons whether conventionally produced or genetically engineered remains morally repugnant.¹⁸

In 1975, at the Asilomar conference, geneticists concluded:

We believe strongly that the construction of genetically altered micro-organisms for any military purpose should be expressly prohibited by international treaty, and we urge such prohibition be agreed upon as expeditiously as possible.¹⁹

Eliminating this risk should involve the development of a code of ethics that includes mandatory publication of all research findings. An end to such secrecy also would benefit science itself in that the free exchange of ideas and information could lead to greater progress in the pursuit and dissemination of knowledge. However, we recognise that today in an age of excessive competition and free market practices, scientists may be prevented from sharing information until a stage is reached in the research where their work can be patented.

The *Catechism of the Catholic Church* (§2292) clearly states that:

scientific, medical or psychological experiments on human individuals or groups can contribute to healing the sick and the advancement of public health. Research or experimentation on the human being cannot legitimate acts that are in themselves contrary to the dignity of persons.

¹⁸ J. Rifkin, The Biotech Century: How Genetic Commerce Will Change the World (London: Phoenix, 1998), 91-96.

¹⁶ NCCB Science and Human Values Committee, "Critical Decisions: Genetic Testing and its Implications," *Origins* 25.45 (May 2, 1996).

¹⁷ Suzuki and Knudston, *Genethics*, 162.

¹⁹ Suzuki and Knudston, Genethics, 239.

Scientists in general have voiced concern about biological warfare. Hepburn strongly argues against the patenting of genetic information, stating that "generally, the patenting of human genetic material has been rejected as it is tantamount to slavery."²⁰ Just as it is immoral for one human being to own another in slavery, so too it is deemed as immoral and unethical for one group to have exclusive rights to the information gained from HGP over another. Such information should be the property of all humanity, not just the property of an affluent section within it. An additional ethical concern is that the HGP, given its scientific nature, aims to dissect humanity at a molecular level, and as such has obvious limitations. The complexity of human life must not be recognised solely in terms of its biochemistry, but be recognised in terms of the holistic nature of what makes humanity truly human. One cannot reduce life merely to the sum of its chemical components.

The renowned Australian jurist, Justice Michael Kirby notes that several legal considerations also need to be considered in respect to the information derived from the HGP.²¹ While it is not within the scope of this paper to discuss them in depth, it will be useful to note the ethico-legal issues raised by this new technology. Kirby proposes several questions:

- (1) How do we protect the confidentiality of genetic information?
- (2) Does proof of a genetic propensity to violence help to exculpate the criminal who may be merely acting out genetic predisposition?
- (3) Should scientists be able to obtain patents of the map of the human genome even before they have identified the significance of the markers on that map for particular characteristics or medical conditions?
- (4) Should the genome belong to all humanity as a "gift of God" or nature to us all?
- (5) Should employers and insurers be entitled to conduct intensive genomic investigations to reveal the potential risks which may be faced in the distant future by the employee or the insured?
- (6) Should a person be entitled to refuse to unlock his or her genetic future, preferring to live in happy ignorance of genetic disorders rather than to take the risk of melancholy discoveries?
- (7) How should we control manipulation of animal and human genes?
- (8) Are there risks which we cannot yet predict in interfering with the germline by which genetic messages are sent from one generation to the next?

According to Justice Kirby, many of these questions not only provide a moral dilemma in which precedent and tradition have little answer, but also present a developing legal mine-field, especially in the area of potential litigation. Some of these issues are taken up under the headings below.

Genes and Criminality

In his deliberation on ethico-legal problems raised by genetic engineering, Justice Kirby puts forward a case-study on the legal aspects of a scenario where a criminal's behaviour

²⁰ Hepburn, Of Life and Death, 96.

²⁰ Hepburn, Of Life una Deam, 90

²¹ M. Kirby, "The Challenge of the Human Genome Project," Australian Biologist, 9.3 (1996): 104.

may be found to be caused by a genetic component.²² Scientists have for years pondered on the possible genetic links to crime. Those espousing the link often fail to take into account the multifaceted aspects of the problem which, alongside the genetic possibilities, also include sociological, psychological and environmental factors. As yet, the scientific data do not support any link; one needs to understand that many human characteristics are polygenic and thus it is dangerous to declare a causal relationship between a gene and a certain human behavioural trait or characteristic (Norman 2003).²³

The attempts to link traits such as intelligence, aggression and criminality with genes show that the evidence has been much less convincing than studies that have shown the link between physical characteristics and disease to genes. The connection between crime and genetics probably has its source in the often-quoted causal link between aggressive prisoners and a chromosomal abnormality known as XYY. Suzuki and Knudtson dismiss such a theory, as they point out that 96% of XYY males "are thought to lead relatively ordinary lives, never seeing the inside of a prison or mental institution." Clearly there is a need to appreciate that there are complexities that "underline human difference; we are often too quick to judge one another on the basis of fragmentary genetic clues." Thus, the idea of linking genes and criminality is dangerous, and is perhaps a throwback to the 1930s - 40s where the Nazi regime developed a broad policy of eugenics in which a number of socially and culturally unacceptable behaviours were incorrectly linked to genotypes and genetics. In this way, that State could justify the discrimination against Jews, Gypsies, homosexuals, non-Nazis and in fact anyone who opposed it.

A Genetically Tailored Human Race?

The genetic selection and breeding of human beings to produce predetermined traits is known as eugenics. Any racist or government policy that promotes a genetically tailored human race is inherently evil, as individuals, with all their diverse characteristics, are not respected, nor valued, and are seen merely as the property of the State. In such cases, a human being is reduced to the status of a non-being - a non-person being denied the right to develop individual, full human potential with the right to make free, informed decisions. Eugenics relies on flawed assumptions and ideologies to undergird it, which in themselves are sources of inequality and injustice.

Where does one draw the line in genetic research? Though we see the present benefits of genetic engineering to treat disease, perhaps even history would have shown humanity and civilisation to be poorer as a result, had such procedures been available in the past. For example, Justice Kirby muses: "If the deafness marker were found and eliminated, might we lose a Beethoven? If the blindness marker were found, would we lose a Milton? ... How many great spirits of the past would have been eliminated?" Perhaps this is a forewarning, and a *caveat*: we must carefully reflect on the principle that the deliberate selection of characteristics in the unborn may be a dangerous path for human civilisation to take.

²² Kirby, "The Challenge of the Human Genome Project."

²³ Norman, G. "Genes, Experience and What Makes Us Human," http://www.thegreatdebate.org.uk/Gillreview1.html, (2003).

²⁴ Suzuki and Knudston, Genethics, 155.

²⁵ Suzuki and Knudston, Genethics, 155.

²⁶ Kirby, "The Challenge of the Human Genome Project," 104.

Prenatal Screening

In the Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation (Donum Vitae 1987), the Sacred Congregation for the Doctrine of Faith argued that "if prenatal diagnosis respects the life and integrity of the embryo and the human foetus and is directed toward its safeguarding or healing as an individual", then the procedure can be considered morally licit by applying the ethical *Principle of Double* Effect. It also argued that the procedure must not involve disproportionate risks to the unborn child. The main concern that the Church holds is that such prenatal procedures may be linked to abortion. The Church views as immoral an expectant mother submitting to prenatal testing for the purpose of eliminating a foetus which is affected by malformations or which are carriers of hereditary illness. Such purposes are interpreted as having much in common with the policy of eugenics. The *Instruction* further adds that if the intent of the screening is for potential abortion rather than for therapeutic purposes, the procedure "is to be condemned as a violation of the unborn child's right to life and is an abuse of the prior rights and duties of the spouses." Cases have occurred where normal babies have been aborted on the basis of prenatal screening results. Thus clearly one needs to recognise that the procedure is not always one of total certitude. However, some ethicists such as the Australian, Peter Singer have posed a counter-argument: is it ethical or moral knowingly to bring into the world a severely physically or mentally deformed child?27

A Case for Genetic Intervention

A medical condition called Cystic Fibrosis (CF) is a disease that is inevitably fatal to those afflicted by the age of about 30 years. This condition affects the epithelial tissues of the lungs and digestive tract, and is known to have a genetic cause. It is now known that in the Australian general population, 1 in 22 people carry the CF gene and where each parent is heterogenous for the condition it will lead to a 1 in 4 chance of the offspring being homozygous for CF, thus inheriting the condition.²⁸ This means that 1 in 1800 births in Australia are afflicted with this disease. Amniocentesis and molecular biology techniques are already available to determine if the foetus is positive for the CF gene in the early first trimester of pregnancy. This now leaves the parents of the unborn free to make a decision as to whether to continue with the pregnancy. While this is indeed an emotional and to some extent philosophical argument, it raises further questions.

Where is the line drawn on what constitutes deformed, sick or unhealthy foetuses? Does someone with a gene for asthma qualify for "elimination"? If one uses this specific example, is the gene for asthma a gene that may at times cause asthma only if certain environmental factors are present and bring about an attack? In this case, the role of the gene may be secondary to environmental causes, and as such this gene may even have an evolutionary advantage to the species as a whole. If many such genes are being switched on in so many individuals, it perhaps indicates that we have radically and rapidly changed our environment from the one that we were meant to thrive in. In short, does the gene merely signal a wider problem, in which the environment or some other factor, rather than a gene, is the primary problem?

²⁷ P. Singer, Writing on an Ethical Life (London: Fourth Estate, 2000).

²⁸ K. Drlica, *Understanding DNA and Gene Cloning: A Guide for the Curious*, 3rd ed., (Wiley, 1997), 258.

Thus, the foundational ethical principle to consider remains: respect for the individual. Perhaps we need to look at a holistic conception of the human person rather than focus on what physically defines them. In other words, we need to consider human personhood in its entirety, that is, in all its physical, emotional, intellectual, spiritual and social dimensions.

Cloning of Human Beings

Australia, along with much of the international community, currently bans the cloning of human beings. The same technology that produced 'Dolly the sheep' conceivably could be utilised in the cloning of humans. From a scientific view, this practice would be considered dangerous. First, as the genetic material from the donor is already of a certain age, the DNA of the cloned human would too be aged and there would be a real possibility of premature aging as well as an increase in genetic deformities. This already had been noted in "Dolly."²⁹ Secondly, from an ethical and religious perspective, it must be asked whether such procedures are in accordance with God's will and the dignity of human life. Given the almost universal ban on such genetic procedures, ethicists, politicians, legislators, and scientists currently have grave reservations about the morality and efficacy of such actions.

The Human Stem Cell Debate

Human Stem Cell research and therapy are divided into two possibilities: the use of embryonic stem cells or adult stem cells. Stem cells by definition are pluripotent; that is, they are the most primitive cells in the body, which give rise to all other cells. Theoretically they can be transformed into any of the 200 or so different cells that form tissue and organs in the human body. The use of adult stem cells is less problematic than embryonic cells, both from a scientific and moral stance. Adult stem cells can be obtained without causing death to the donor. The cells, being antigenically the same as the donor, will not pose any immunological problem if used for therapeutic use in the donor. For example, it may eventually be possible to use adult stem cells from a diabetic person, develop them into pancreatic cells, and then transplant them back into the donor. It is supposed that these cells would not be rejected by the body and would produce insulin, thereby curing the diabetic condition (Cromie, 2001).³⁰

Unfortunately, the present use of embryonic stem cells poses several problems. As they are derived from very early embryos, by definition they will not be used in therapeutic treatments of the donor, and thereby will elicit rejection reactions commonly found in normal transplants of foreign tissue. For those who regard life as starting from conception, that is, the initial fertilisation leading to the formation of the zygote and subsequent mitotic divisions, this amounts to destruction of human life. However, the ethical counter-argument is that many do not accept this definition regarding life's origins. In addition, the banning of this research may inhibit or block completely important scientific research that could lead to new treatments and cures of various

 30 W.J. Cromie, "Adult Stem Cells Effect a Cure," $\underline{\text{http://www.news.harvard.edu/gazette/2001/08.16/01-stemcells.html,}}$ (2001).

²⁹ N. Robertson, "Cloned Sheep Dolly has 'Old' DNA" – *CNN Report*: http://www.cnn.com/NATURE/9905/26/dolly.clone.02/, (1999).

diseases. The use of human embryonic stem cells in such research, continues to divide the community as to whether their use is ethical.

It may well be that science resolves this problem itself in the future. Current research is attempting to transform normal cells back to their original embryonic stem cell state; these cells can then be further transformed into another type of cell. For example, a skin cell could be transformed back into a stem cell, in turn, that could then be transformed into a liver cell. If this technique succeeds, the ethical argument concerning the use of human embryonic cells would no longer exist. On-going research suggests that certain ordinary body cells may be induced to have the same properties of embryonic stem cells.³¹

Conclusion

In conclusion, it is evident that the science of genetic engineering and manipulation is already available. It will shape society now and in the future. As we have shown, a number of genetic applications are possible and the morality of each application must be examined in the light of the specific circumstances under which genetic intervention is utilised. Theologians and ethicists have a vital role to play in proclaiming the dignity and the rights of each human person. They should endeavour to understand the complexities of the emerging sciences and must work closely with philosophers, jurists, scientific bodies, medical associations and the providers of genetic technologies, so that workable guidelines, code of ethics, and regulations are enacted that will prohibit certain negative and destructive applications of the technology.

Such legislation may no doubt be controversial, as one only has to note the polarisation that took place recently in Australia in respect to the stem cell debate. Nevertheless, the use of genetic engineering and manipulation needs to operate from an ethical framework that recognises the rights and dignity of each and every human individual. The benefits of this technology need to be weighed up against possible harmful effects for the individual and for society in general. Competent individuals must be fully informed so that their consent be as reasoned as possible. Few moral questions are "black and white"; the "grey" areas must be explored and decisions made within an ethical framework that is socially responsible, equitable and just. We must also acknowledge that in the pluralist culture in which we live, there will be many voices that will proffer different and even contrary perspectives and views, and that the search for cohesion, justice and compassion is also a struggle for Christian as well as human values and principles.

It is important to realise that the benefits of genetic technology should benefit humanity in areas such as individual medical therapy and the improvement of food availability, particularly in economically deprived areas. Genetic engineering for corporate power, or as a means of warfare, or of depriving certain individuals or groups from insurance cover must be seen as morally suspect. All uses of this technology nevertheless need to be monitored by responsible governments, legislators, and scientific organisations with a view to maintaining safeguards against possible detrimental effects of the technology. However, this may not be enough. It is equally the responsibility of each competent individual to be morally aware when confronted with issues related to genetic

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³¹ Johns Hopkins University, "Stem Cells to your Rescue," http://www.hopkinsafter50.com/html/newsletter/haFeature.php. (2003).

engineering; this then enters into the domain of ongoing moral, ethical and theological education.

Both genetic technology providers and recipients need to clearly appreciate that this is a new technology - and much is still hidden in the realm of the unknown. Caution, reasoned use, appraisal and re-appraisal need to be exercised to ensure that the technology is not misused. Rather, the integrity of the natural environment and biodiversity need to be protected and preserved; principles of non-maleficence, autonomy, beneficence and justice need to enshrined; and overall, the use and advances of genetic science need to enhance the goodness and quality of human life.

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