9 Medical Ethics 3

Genetic Engineering and Embryo Research

WHAT YOU WILL LEARN ABOUT IN THIS CHAPTER

• An understanding of genetic engineering and embryo research, and the issues involved.
• The idea of the sanctity of life and how it applies to embryo research.
• Religious approaches to genetic engineering and embryo research.
• The ethical implications of our knowledge of the human genome.
• The approaches of different ethical theories to genetic engineering and embryo research.

KEY SCHOLARS

• Thomas Aquinas (1225–1274)
• Immanuel Kant (1724–1804)
• Jeremy Bentham (1748–1832)
• John Stuart Mill (1806–1873)
• Peter Singer (1946– )
• Celia Deane-Drummond
• Joseph Fletcher (1905–1991)
• Jonathan Glover (1941– )
• Paul Ramsay
• Robert Song (1962– )

Essential terminology

Blastocyst
Cloning
Embryo
Genetic engineering
Germ line engineering
Human genome
Somatic cell engineering
Stem cell
Therapeutic cloning
Zygote

Study hint

Many of the issues in biotechnology are shifting all the time as science and technology move forward. To stay abreast of these issues it is a good idea to keep a folder of relevant newspaper cuttings and annotate them with how you think the different ethical theories would react to the issue.
WHAT IS GENETIC ENGINEERING?

Genetics is about our genes, which are made of DNA and are the basic building blocks of life. Every cell has a full set of genes, carried in strands of DNA which are chromosomes. When new cells are replicated, each new cell has characteristics passed on by the DNA – genes are like a blueprint of life. In humans the genes decide the characteristics inherited from each parent.
It was in the mid-1970s that scientists first discovered how to move pieces of genetic material from one species to another – this came to be called genetic engineering. Some said that this was simply an extension of what breeders of plants and animals had been doing for hundreds of years and what nature did through evolution and natural selection, but others claimed that it was ‘playing God’ and was unnatural. Genetic engineering, however, continued to develop, and the technology was extended from plants to animals and finally to human cells. Today genetically altered crops, such as soybean and maize, are grown extensively, especially in the USA, and marketed all over the world. Scientists working for pharmaceutical companies use altered genes to produce ‘designer’ drugs, and research is gathering pace to treat certain inherited diseases by gene therapy.

The ethical questions first aired in the 1970s continue to be raised, both about the process itself and about the results. Others will say that humans have always altered their environment to benefit themselves, and this new biotechnology could help fight hunger and disease.

WHAT IS EMBRYO RESEARCH?

Embryo research has as its aim to find cures for serious illnesses using tissue or cells from embryos. Most of this research concentrates on stem cells and the field of regenerative medicine – the repair of damaged organs and body parts. Stem cells can change into other types of cells such as heart cells, muscle cells, nerve cells or skin cells. The ultimate stem cells are the system cells in the early embryo because they can develop into every single cell type. There is very little debate over the use of adult stem cells which can be taken from body tissue without harming the patient; so far these are the only ones which have successfully helped patients. Embryonic stem cells are removed from early embryos in a process which destroys the embryo – this makes it inherently problematic as far as ethics is concerned. These embryonic stem cells may be taken from embryos left over from IVF treatment or created in a laboratory from donated sperm and eggs. At the present state of the science no cure has been achieved using embryonic stem cells and they will always cause problems, as they do not have the same genetic make-up as the patients and will be rejected unless anti-rejection drugs are used. So the best option, at present, is to make new embryos by therapeutic cloning – the same method as used to create Dolly the sheep. This of course gives rise to another problem – the potential of this development is limited by the supply of human eggs and possible exploitation if poor women are to be paid for eggs.

Reproductive cloning has been tried in animals and there have been some successes after many, many failures. The only dividing line between therapeutic cloning and reproductive cloning is the intention of the scientists.
In the UK the law is clear: embryos may not be experimented on past fourteen days; a human embryo cannot be placed in an animal; human cloning is not allowed; the genetic structure of any cell cannot be altered while it is part of an embryo.

The Human Fertilisation and Embryology Authority allows embryo research for the following purposes only:

- to promote advances in the treatment of infertility
- to increase knowledge about the causes of congenital disease
- to increase knowledge about the causes of miscarriage
- to develop more effective techniques of contraception
- to develop methods for detecting the presence of gene or chromosome abnormalities.

For the purpose of this book we will look at genetically engineered crops, genetic selection, genetic testing and screening, the alteration of human genes, stem cell research, and whether the Human Genome Project understands humans primarily in terms of their genetic inheritance.

**GENETICALLY ENGINEERED CROPS – ‘FRANKENFOOD’?**

The production of genetically modified (GM) crops has led to very strong reactions. In the UK press they were called ‘Frankenfoods’ after Mary Shelley’s scientist and his manufactured monster.

These GM crops have certain obvious advantages: the food has better taste and quality and a greater resistance to pests and diseases; it is environmentally friendly in that it does not require chemical pesticides and will conserve soil, water and energy. The most talked-about advantage is that these GM crops offer the world’s best chance to end or at least greatly reduce hunger and malnutrition through greater yields and sturdier crops.

However, critics say that these GM crops threaten the environment and may cause havoc through cross-pollination. Genetically engineered crops could have as yet unknown effects on human health by causing unexpected allergic reactions and eventually reducing resistance to disease and transferring antibiotic resistance markers. A potentially more serious criticism does not concern the effects on the developed world, which can protect itself, but on the developing world: many poor farmers are encouraged to grow GM crops. Giant multinationals such as Monsanto and Novatis own patents on these altered crops and demand that farmers buy new seeds each year at great expense instead of reusing seeds from the previous year’s crop. One country that has stood out against this is Zambia, which does not have
enough food of its own but refuses to import from the USA and rejects any seeds or foods that have been genetically modified. This decision is partly to protect its export of vegetables to Europe and partly a response to health warnings and damage to the environment; it is also concerned that this new biotechnology is part of a globalized system of agriculture which favours large producers and argues that it is more important to retrain small farmers to farm organically as they did in the past.

Finally, GM food cannot be seen as the sole solution to world hunger — that problem is far more complex, and questions of injustice in the social situations of today’s world need to be examined.

SELECTING HUMAN GENES – ‘DESIGNER BABIES’?

The ethical debate surrounding the selection of human genes is even more complex than that over GM foods. There are a number of reasons why embryos are selected: to screen for genetically inherited diseases such as Huntington’s disease, Tay-Sachs and cystic fibrosis or for genetic conditions such as Down’s syndrome; to create a healthy baby to treat a sick sibling; or to select the sex of the child (this is illegal in the UK).

In order to do this, embryos are created by in-vitro fertilisation and a single cell is removed from each for genetic testing; one embryo is selected for implantation and the rest discarded.

Case studies

In 2002 a British couple, Michelle and Jayson Whittaker, asked the Human Fertilisation and Embryology Authority if they could genetically select an embryo which would be a match for their son Charlie, who had a life-threatening blood disorder. They were refused permission and went to the USA for IVF treatment.

In 2003, however, the Hashmis, who also had a son with a rare blood disorder urgently needing a bone marrow transplant, were granted permission to select an embryo after many months of wrangling in the courts.

- Is this just a brilliant way of saving a child’s life?
- Are scientists ‘playing God’?
- What about the motivations of the parent?
- How could different ethical theories approach these situations?
Sex selection

The Mastersons have sons, but their only daughter died, and they want to use sex selection to have another daughter.

- If they want a daughter so badly will they just want her to be like the daughter they had? Will this damage her?
- Can we even begin to know their motives?
- Would we feel differently if the sex selection was for medical reasons (e.g. to select a female to have a baby free from the haemophilia gene)?

Genetic screening, and the idea of ‘designer babies’, involves destroying unwanted and unsuitable embryos. If the embryos are seen as persons from the moment of conception and, therefore, as having an intrinsic dignity and value that cannot be compromised in the name of other values, then any destruction of embryos would be opposed. However, fertilisation is a process that takes about twenty-four hours to complete and so there is no specific moment when personhood may be said to be conferred. Peter Singer points out that up to fourteen days after conception the fertilised egg has the capacity to divide into two and become identical twins. In some cases it has been observed that such divided eggs blend back together into one blastocyst. If the egg is fertilised in vitro, one cell can be removed to have its genetic structure tested and the developmental process is unharmed. In fact, all the cells of the blastocyst can be separated and each has the capacity to become a whole human being – this is important as the blastocyst does not have true individuality. Without individuality it is difficult, according to Singer’s argument, to see how the organism can be a person. However, even if the early embryo is not a person with full human rights, we do not yet have enough knowledge of early brain activity to know whether an early embryo feels pain.

Some people are concerned that the newborn baby will be subject to painful medical procedures to help a sibling, but, in fact, the necessary cells are taken from the umbilical cord. There are also concerns that, in an increasingly materialistic society, the baby is being treated as a commodity – just made to be a donor or to fulfil parental desires. As it is so difficult to assess the motives of others, some may say that embryo selection is the beginning of a ‘slippery slope’, with babies ultimately being chosen for eye colour or intelligence. However, we have been doing the same to animals for hundreds of years – would the selection or enhancement of humans be any different?
TESTING AND GENETIC SCREENING

Genetic testing

Scientists have created tests for various genetic diseases – for example, whether a patient is carrying the gene which produces breast cancer or sickle cell anaemia. Patients have to agree to the tests and understand the implications of the test should they prove positive. One of the main ethical questions is whether the tests should remain private or whether the results should be divulged to employers or insurance companies. If the government goes ahead with plans for an identity card which carries genetic information, it would be difficult to keep such information private and could lead to discrimination. Genetic problems could also affect other family members – should they be informed if they have not given consent? Gene testing usually gives only a probability of developing the disorder and a limitation of all medical testing is the possibility of laboratory error.

Genetic screening

Genetic testing is done on sections of the population who are known to be at risk – this may be done on an adult, a child or a foetus. There are some advantages in knowing, in that the person can be encouraged to change their lifestyle to reduce the danger of developing the disease. However, it may lead to discrimination against certain groups, such as the wish of a Jewish committee in New York to prevent Ashkenazi Jews who carry the Tay-Sachs gene from marrying each other. It may also lead to aborting a foetus which has a genetic flaw, which may prevent the child from pain and suffering but which also raises questions about how we as a society define ‘normal’ and ‘abnormal’. If, for example, scientists were to discover a gene for being born violent, should we test everyone to see if they are carrying the gene and then eliminate them to make society a safer place?

Gene therapy

A further problem involves the use of gene therapy to correct, alter or replace genes. This has proved successful in some areas but also causes problems, as in the case of sickle cell anaemia which is prevalent among Afro-Caribbeans – this gene affects a few in a terrible way but it is the same gene which gives natural immunity from malaria.

There is also the issue of the allocation of health resources and how they are used. Can genetic screening be justified for a few individuals? Can it be justified if there is no cure available, e.g. Huntington’s disease? How do we
even know what to test for as more and more diseases are discovered to have genetic links?

**THE ALTERATION OF HUMAN GENES**

Gene therapy aims to cure or ultimately prevent disease by changing genes. The science is only in its infancy and primarily experimental. Gene alteration can be targeted to somatic (body) cells, in which the patient’s genome is changed, or to germ (egg and sperm) cells, in which the parent’s egg and sperm cells are changed with the aim of passing on the changes to future generations. **Germ line** therapy is often confused with genetic selection, but it is not, in fact, being actively investigated in larger animals or humans. Ethically this therapy is questionable, as it could ultimately change the whole of humanity and what it means to be human – we take charge of our own evolution.

The alteration of genes in a patient’s **somatic cells** was first used successfully in 1990 – this type of genetic therapy raises the fewest ethical questions, especially when it is used to treat a life-threatening disease. However, gene therapy given to a foetus before birth could again mean that we decide which genetic predispositions are to be altered – for example, at present conditions such as obesity, below-average intelligence and poor eyesight are seen as normal inheritable characteristics, but in the future may be considered to be grounds for alteration or even abortion. Some people feel that there is no difference between gene alteration to prevent a minor disability and paying school fees so that children get a first-class education. This may of course create a further ethical issue whereby a division is created between the genetically rich and everyone else.

However, most diseases involve the interaction of many genes and the environment. Many people who develop cancer not only inherit the disease gene, but may not have inherited particular tumour-suppressing genes. Diet, exercise, smoking and other environmental factors may all have contributed to their disease. Studies of identical twins show that individuals with the same genetic make-up do not develop the same diseases – environment plays a part.

**STEM CELL RESEARCH**

Stem cells are cells that can change into other types of cells – in the very early embryo they are totipotent: they can become any kind of body cell; in the adult they are pluripotent: they have the capacity to become a variety of cells, but not all. Adult stem cells can be taken from an adult, a child or even from the placenta of a newborn baby without harming the patient, but those
1. Nucleus carrying patient’s own genetic material removed from skin cell

2. The nucleus is then injected into a donated human egg, which has its own nucleus removed.

3. Electricity and growth factors trick the embryo into dividing.

4. After 5 days, the embryo reaches the Blastocyst stage of 100 cells.

5. Embryonic stem cells are master cells with the potential to form any tissue in the body.

6. The stem cells can then be transplanted, without rejection, into the specialised tissue.

Brain to cure Parkinson’s

Pancreas to cure diabetes

100 stem cells

Two diagrams of stem cell research
1. Stem cells taken from adult tissue
2. Stem cells multiplied with growth factors on a culture dish
3. Developed into specialised cells
4. Embryo allowed to develop
5. Stem cells removed and cultivated into specialist cells
6. Injected into damaged part of the body

1. Cell taken from patient
2. Donor egg nucleus removed
3. Replaced by nucleus from patient's cell

Muscle cells
Blood cells
Neural cells
removed from early embryos destroy the embryo. There are also foetal stem cells which are taken from aborted foetuses and are believed to have almost the same potential as embryonic stem cells.

Scientists hope that stem cells can be used to cure many disorders such as Parkinson's disease, diabetes, spinal cord injuries, heart disease and cancer – but all this is a long way off, decades in the future. In 2006 it was reported in the Lancet how, five years previously, patients' own cells had been used to grow and replace bladders in seven children who suffered from spina bifida. These were not stem cells, but more specialised cells which can only grow into bladder cells. This has improved the lives of these children beyond measure, and they do not have to take anti-rejection drugs, as the bladders are made from their own cells. A bladder is a much simpler organ than a liver or a kidney, but they are now testing kidneys successfully in cows. This is a very different situation from the use of embryonic stem cells, which necessitates the destruction of embryos for the benefit of others, which goes against the teaching on the sanctity of life.

Embryonic stem cell research is the threshold of cloning – first developed at the Roslin Institute by Ian Wilmot in 1997, when Dolly the sheep was cloned. Human cloning is illegal in the UK, but several rogue scientists have attempted it elsewhere. Scientists simply say that it is unsafe for the cloned child, as, from the experience of cloning other mammals, producing one child might need hundreds of pregnancies and many abnormal late-term foetuses could be produced. Others oppose human cloning on the grounds that it would produce confusion in family relationships and encourage parents to see cloned children as objects rather than independent human beings. However, the problems will eventually be overcome and many will argue that cloning is a possible solution for infertile couples, and that clones would simply be like identical twins, which are natural clones of each other.

Many scientists now say that it is unnecessary to use embryonic stem cells in their search for cures:

- Embryonic stem cells are very 'plastic', which means they can be unstable and become malignant, causing cancer.
- Adult stem cells are found in umbilical cord blood and placenta blood, as well as virtually every major organ of the human body.
- Adult stem cells have already been successfully used in treatments, while embryonic stem cells are still at the theoretical stage.
- The benefits of embryonic stem cells are a long way off.
- Adult stem cells overcome the problem of immune rejection.
- With the rise of animal rights activists and the problems involved in using adults to test drugs, it is likely that embryos will be used less for actual research and more for testing by pharmaceutical companies.
THE HUMAN GENOME PROJECT – A LIMITED VIEW OF HUMANITY?

Robert Song asks whether the human genome project and the resulting advances in biotechnology simply reduce human beings to their genetic inheritance. He does not criticise the science itself, nor does he say that the new genetics is intrinsically reductive in itself. He sees the developments in genetics as shaped by what he calls the ‘Baconian Project’ – the aim to eliminate suffering and maximise choice. This view may be traced back to the rise of the natural sciences in the seventeenth century (and also follows Francis Bacon’s emphasis on the necessary social use of scientific knowledge), the Utilitarianism of the eighteenth century and the Romantic emphasis on individual fulfilment and autonomy. The result of this is that all suffering is seen as pointless (the rise in a desire to legalise euthanasia could follow from this), which has brought about an increase in the number of medical interventions and an understanding of our bodies as things to be changed according to our individual tastes through plastic surgery and so on. The human genome project has given us not just the knowledge of the ‘basic building blocks’ of the body and how it is constructed, but also the knowledge of how it may be reconstructed.

APPLYING ETHICAL THEORIES TO GENETIC ENGINEERING AND EMBRYO RESEARCH

Religious ethics

The sanctity of life is a key theme with which to approach the questions of genetic engineering and embryo research. The Bible teaches that God created the human in his image and so human life has intrinsic value. Using an embryo for the sake of another human is wrong, as the embryo has intrinsic worth. Any technology that creates spare embryos to be used or discarded is wrong. However, there are not the same objections to using adult stem cells or to the modification of animals or plants.

Catholic ethics are based on Natural Law and so are positive about advances in science that improve human life, but never at the expense of human life, which is sacred from the moment of conception. The Catholic Church also expresses concern about who is investing in the research and who will benefit from it. However, the Catholic Church recognises the need for humans to use their God-given intelligence to transform and humanise the world. This was the view of Pope Pius XII when he justified the use of painkillers: ‘Man preserves, even after the Fall, the right of dominating the forces of Nature, of using them in his service, and of employing the resources so offered to him to avoid or suppress physical suffering.’
Catholics claim that certain actions are intrinsically evil, as they go against what it is to be human. Evil is seen as falling short of what humans are intended to be and is a result of free will. They make a distinction between doing evil and suffering an evil. Humans that are physically impaired (e.g. are blind or have Down’s syndrome) are suffering an evil because they fall short of what it is to be fully human. Correcting these impairments is therefore a good thing – but the use of genetic engineering to achieve this is still ruled out. There is also concern that too much stress is placed on being physically perfect and the spiritual side of what it means to be human is neglected.

The Catholic Church rules out embryo research as being unnatural and destroying life, but it approves of genetic engineering which respects human life and human rights on the basis of its help for the individual and society.

Other Christian churches may take a different view and follow a Situation ethics line based on agape. An action is good if it is based on love and bad if it is based on selfishness. Two influential Protestant writers on bioethics were the Episcopalian Joseph Fletcher and the Methodist Paul Ramsay. Fletcher saw a human being as ‘a maker and a selecter and a designer’ who acts morally when in control of genetics. He was not opposed to IVF and therefore it could be concluded that embryo research is the most loving thing to do with spare embryos when the only other option is to destroy them, especially when such research could lead to cures for terrible diseases. However, creating embryos for the direct purpose of stem cell research is difficult to justify as being the most loving action.

Ramsay opposed separating procreation from conjugal love and was pessimistic about our attempts to ‘play God’, but his arguments were always teleological and looked at the benefits for humanity of genetic engineering. He approved of genetic screening as doing ‘more good than harm’ and said it was important that ‘the benefits from any course of action must be weighed up against any risk’.

Christians in general seem to look favourably at genetic medicine, while acknowledging both the risks and the limits that should be imposed on research in terms of respect for human life.

Natural Law

Basic principle – everything is created for a purpose and when this is examined by human reason, a person should be able to judge how to act in order to find ultimate happiness.

Natural Law has the primary precept of self-preservation and from this may be deduced the secondary precept ‘no embryo research’, as it destroys life.
However, it could be argued that the research can be justified, as it preserves life by curing diseases.

**Utilitarianism**

*Basic principle – the greatest good for the greatest number.*

Utilitarianism does not accept the principle that human life has absolute value and this should be upheld whatever the consequences, but attempts to assess each individual situation on its own merits to promote the greatest happiness for those concerned.

However, Utilitarianism only works if it is actually possible to assess the results of genetic engineering and embryo research and decide whether they favour all concerned. In practice this is difficult, as we cannot predict all consequences. However, it is possible to say, from a utilitarian point of view, that it is better to save many lives in the future by embryo research at the cost of a few embryos now.

Bentham’s hedonic calculus can only be applied to those who suffer. Early embryos, it is assumed at the present stage of knowledge, do not have the capacity to feel pain and so cannot be measured according to the hedonic calculus. However, the benefits of genetic engineering and embryo research are justifiable using the hedonic calculus – the pleasures brought about by cures for diseases such as Parkinson’s outweigh the cost to the embryos. However, the costs to the Health Service, as mentioned above, also need to be considered and the likelihood of success taken into account.

**Kantian ethics**

*Basic principle – the categorical imperative: universal maxims; treating others as ends in themselves and living in a Kingdom of Ends.*

Kant argued that reason enabled people to impose such laws upon themselves and when the categorical imperative is applied to genetic engineering and embryo research there are immediate difficulties: both would be hard to universalise simply. For example, it would be possible to universalise the maxim ‘use spare embryos left over from IVF for stem cell research’ but not ‘create embryos for stem cell research’, as there would be no embryos left to reproduce and the human race would die out.

There is also the emphasis on treating people as ends in themselves and not as a means to an end – embryo research would also go against this if the embryo is considered to be a person. Kant was not clear on the moral status
of embryos. However, the Kantian idea of respect for persons and the requirement for human rights to be respected, that informed consent should be obtained and so on will mean that genetic medicine, testing, screening and adult stem cell research will be truly humanising. Respect for autonomy and privacy is also essential to Kantian ethics.

Kant's stress on acting out of duty alone, with no account taken of compassion or love, means that all consequences are ignored, whatever they may be.

**REVIEW QUESTIONS**

*Look back over the chapter and check that you can answer the following questions:*

1. Explain the differences between therapeutic and reproductive cloning.
2. How could genetic engineering be used to alleviate world hunger? What are the problems with this?
3. Explain the difference between adult and foetal stem cells – why is this important ethically?
4. Take a current newspaper article about any form of genetic engineering or foetal research. Stick it on a piece of A3 paper and write brief notes around it on how different ethical theories would approach the issue.
5. List some of the ethical problems with genetic engineering and foetal research.

**Terminology**

*Do you know your terminology?*

Try to explain the following key terms without looking at your books and notes:

- Blastocyst
- Cloning
- Germ line engineering
- Somatic cell engineering
When writing answers about genetic engineering, make sure you know and understand the terminology and can explain the ethical implications of genetic engineering.

**SAMPLE EXAMINATION QUESTIONS**

(a) Explain how Utilitarianism might be applied to embryo research. (25 marks)

- You need to begin by explaining Utilitarianism – the amount of pleasure or happiness caused by an action.
- You should explain that Utilitarianism is teleological and focused on consequences – an action is right if it produces the greatest good for the greatest number.
- You should then apply this to embryo research – balancing good over evil and bringing benefit to sufferers of inherited diseases.
- You need to explain that a utilitarian would look at the merits of each situation, but would also need to consider the costs involved.

(b) To what extent can embryo research be justified? (10 marks)

Here you need to contrast and analyse the different approaches:

- You could defend embryo research, as it brings relief to sufferers and improves their quality of life, curing diseases that were once thought incurable.
- On the other hand, you may question the techniques and the misuse of spare embryos.
- You could explain that some people may object to interfering with nature using Natural Law theory.

**SAMPLE AS EXAMINATION QUESTIONS**

(a) Describe the main strengths and weaknesses of Utilitarianism.

(b) Evaluate a utilitarian approach to genetic engineering.

(a) Explain the differences between a relative morality and an absolute one.

(b) How useful is a relative morality in dealing with issues surrounding genetic engineering?

(a) Explain how the religious ethics you have studied might be applied to the issues raised by genetic engineering.

(b) ‘Genetic engineering is ethically justified.’ Discuss.

(a) Explain Kant’s theory of the categorical imperative.

(b) How useful is the categorical imperative when considering embryo research?
FURTHER READING

Hinman, L. 'Ethics Updates', available at http://ethics.acusd.edu/.