



living counter culturally

talk sheet

Genetic Screening

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let's talk about ...



Pre-Implementation Genetic Diagnosis

New developments in technology not only raise new problems for consideration, they also raise new questions about old problems such as questions concerning the definition of life itself—its commencement and termination.

Sometimes the terms PID (Pre-implantation Diagnosis) and PGD are used almost interchangeably in Anglo-American states. Both are forms of pre-natal diagnosis.

Pre-natal diagnosis means testing for diseases or conditions in a foetus or embryo before it is born. The purpose is to diagnose harmful genetic disorders at the earliest possible stage. Pre-implantation genetic diagnosis (PGD) involves genetically testing an embryo (or occasionally an ovum) in a laboratory.

To achieve this, couples need to have *in vitro* fertilisation (IVF) treatment followed by a genetic testing stage. The aim is to make it more likely that a baby will be born free from a particular condition (usually a disease). This is a means of avoiding pregnancy termination or the destruction of an embryo.

First attempted on animals, PGD was used in 1967 by scientists Robert Edwards and David Gardner to determine the sex of developing rabbits. In the 1980s, human IVF was fully developed, and in 1989, the first PCR (polymerase chain reaction) testing was used for testing of X-linked chromosomal diseases.

The embryo is grown in the laboratory for a couple of days until the cells have divided and the embryo consists of eight cells. At this time one or two of the cells are removed. If the genetic code associated with the condition is known, these cells can then be

tested to see if they contain the faulty gene that causes a particular condition, perhaps one that has a genetic tendency within a family.

One or two of the embryos without a copy of the faulty gene can then be placed into the woman for continuation of its development. Any remaining unaffected embryos can be stored for later use as required. The fertilised cells that are not implanted are usually destroyed. For some, this raises ethical concerns related to when human life begins, the sanctity of human life and the issue of selective abortion.

In an attempt to overcome difficulties related to single-cell techniques, it has been suggested that embryos be biopsied at a later stage of development, thus providing a larger amount of starting material for diagnosis.

The value of PGD is that the probability of having a child affected by the harmful genetic condition is diminished, with no need for a pregnancy to be terminated. If the procedure became more widespread, the incidence of many diseases would be reduced as fewer people with diseases would be born and pass on faulty genetic code to their children.

DISCUSS:

It has been said that genetic screening is the only form of medicine that treats a condition by eliminating the patient.

What do YOU think?

Pre-natal diagnosis

Pre-natal diagnosis involves taking samples from the placenta or the amniotic fluid and examining them for genetic disorders.

Most genetic testing is done through amniocentesis when the foetus is 12 to 16 weeks old. A sample of the amniotic fluid is drawn from around the foetus. A floating cell from the foetus is then found and analysed.

Ethicists express concern that testing might lead to genetic determinism, seeing people as 'victims' or 'architects' of their genes. If testing shows a foetus to be 'genetically defective' then parents might be asked whether they wish to abort. This presents a moral dilemma.



Medical Uses

Two main groups of patients currently use PGD:

1 Couples with a high risk of transmitting an inherited condition.

This may be due to a single defective gene or a chromosomal structural abnormality. In these situations the purpose of PGD is to identify embryos carrying such a defect and destroy them.

The most frequently diagnosed disorders are cystic fibrosis, beta-thalassaemia, sickle cell disease, some forms of spinal muscular dystrophy, Huntington's disease, haemophilia A and others. There are, however, around 4000 known inherited disorders that could be identified through PGD once the genetic code is identified.

2 IVF couples whose embryos are screened for specific conditions.

There are a number of possible future medical uses. Possibilities include the diagnosis of late-onset diseases such as Alzheimer's disease or predisposition to diseases such as obesity, diabetes, heart disease, asthma, cancer and even disabilities such as deafness.

Some seriously ill people could be treated or cured with a bone marrow transplant from a donor identified as suitable through PGD. For example, patients with leukaemia, aplastic anaemia and other potentially life-threatening blood diseases. PGD offers the possibility of selecting embryos that could be grown into suitable donors.

Non-medical uses

PGD has the potential to screen for genetic issues unrelated to medical necessity.

Increasingly, PGD is being used for sex selection. A 2006 survey found that 9% of US clinics provided this service. Half perform it only for 'family balancing'.

Other controversial uses would be if genetic tests for non-medical traits such as hearing, sexual orientation, height, beauty, intelligence or other such factors became available.

There are concerns that PGD could be used as a form of eugenics (the development of particular selected races or populations), which can be defined as 'the science of improving the population by the control of inherited qualities'. This places a negative value on people with certain conditions or qualities when it is seen as 'socially desirable' to prevent further development of certain foetuses.

It may be possible to make other 'social selection' choices in the future.

Financial considerations

The financial implications of medical interventions are often controversial. Some argue, for instance, that PGD could significantly reduce health care costs. Treatment of some genetic diseases can cost millions over the lifetime of a single individual. Some suggest that if births of these individuals could be avoided, then savings would be made.

For example, the lifetime treatment costs for someone with beta-thalassaemia in Britain are estimated at close to £200,000. This is likely to be considerably higher than the cost of tissue typing using PGD to select an appropriate ovum for development and subsequent stem cell transplantation from the resulting infant, although a precise costing is not available.

It must also be recognised that this procedure is likely to be available only to the well off in rich nations while millions in poor nations lack basic health services.

DISCUSS:

The value of life must never be measured purely in monetary terms or without taking other ethical concerns into account.



Ethical Issues

Issues for parents

- There is a need to create and then select embryos on chromosomal or genetic grounds, with the deselected embryos then usually being discarded. This raises issues around the human dignity of the embryo.
- Invasive tests carry a significant risk of miscarriage and foetal death.
- It is not known whether the biopsy of one or two cells correlates with the ability of the embryo to further develop, implant and grow into a full term pregnancy.
- Tests may not provide a precise answer to medical questions.
- Ante-natal testing encourages women to view their babies as commodities that may be rejected if found sub-standard.

DISCUSS:

Lord Winston described creating children to provide stem cells as 'using an unborn child as a commodity'. This objection finds its philosophical foundation in Immanuel Kant's famous dictum: 'Never use people as a means but always treat them as an end.' It is wrong to bring children into existence 'conditionally'.

Issues for offspring

A principle of the Human Fertilisation and Embryology Act is that the best interests of the child produced by assisted reproduction must be paramount. So, what is in the best interests of the child?

- What if a stem cell transplant from an infant developed following PGD is unsuccessful? Would parents unconsciously blame the donor child? What will life be like for the child conceived to produce stem cells?
- Although a child may be born free of a disease, they may be likely to lose the parent from whom the disease-causing gene might otherwise have been inherited.
- There may be unexpected physical side effects and life-long consequences related to the genetic choice that are not appreciated at the time.
- The identification of a genetic mutation may mean that an individual is discriminated against and not able to obtain a job or insurance, obtain a mortgage or find a marriage partner.

Issues for society

Is it harmful to society if families choose their children on the basis of their genetic makeup?

- Opposition to the practice of seeking 'designer babies' raises concerns about eugenics at a societal level. To avoid this it is important that couples and not the state, professionals or other organisations retain control over reproduction and the decision of which children to have.
- Increased ante-natal screening may lead to loss of respect for, and victimisation of, the disabled and their parents.
- 'Tidying away' some hereditary diseases will not make society tidy, nor will it eliminate suffering.
- Some would argue that any attention to the gender of offspring is inherently sexist, particularly when social attitudes and expectations are involved.
- Many disabled people oppose screening because it is very difficult to support a practice that would have prevented one's own existence. Increasingly, disabled people are perceiving these processes as a form of social discrimination against them. Why should we argue that the life of an individual with Downs Syndrome is not worth living, for example?

DISCUSS:

Perhaps embryos would be eliminated that might leave individuals at higher risk for heart disease, stroke, obesity, etc. And there is the possibility that the procedure could be used to eliminate embryos on the basis of gender. There is also the possibility that PGD could lead to the creation of babies for 'spare parts'.

Other ethical issues to consider

Relying on the result of testing only one cell from a multi-cell embryo assumes that this cell is representative of the remainder of the embryo. This may not be the case. PGD may result in a false negative result leading to the acceptance of an abnormal embryo, or in a false positive result, leading to the rejection of a normal embryo.

A genetically-defective fertilised egg, if allowed to mature and cause a live birth, would not necessarily generate a disorder or disease in the individual. The likelihood varies with what is known as the 'penetrance' of the gene. For instance, the gene that causes Huntington's Disease has a 100% penetrance; if you have the 'Huntington's gene', you will certainly develop the disease. Left-handedness penetrance, however, is only about 15%; other disorders or diseases have a penetrance factor that is about 67%.

Thus, many embryos would be killed that would never have caused a disease or disorder.

Dr Anuja Dokras of the Yale University School of Medicine notes that 'this technique is currently available to couples whose offspring are at a high risk (25–50%) for a specific genetic condition due to one or both parents being carriers or affected by the disease. Some genetically-caused diseases only develop symptoms when the person is in their 30s or 40s. By that time, a cure might have been found.' (Source: 'Pre-Implantation Genetic Diagnosis', Pre-Implantation Genetic Diagnosis, Vol. 1 No. 5.)

Some people object to the discarding of unused embryos. They generally feel that human personhood starts at the instant of fertilisation. They view the killing of diseased embryos or embryos with poorly-matched DNA as equivalent to murder.

Other objections concern the fact of selection itself, which may remove some positive traits that are unrecognised.

'Saviour siblings?'

The Law Lords backed a 2003 Court of Appeal ruling that some couples undergoing fertility treatment could have their embryos screened to find tissue matches for seriously ill children. Advocates say the procedure will help save desperately ill children. Opponents fear it could lead to the creation of babies for spare parts.

Children have already been conceived to provide stem cells for their siblings use. PGD is used to select an embryo with the right genetic make-up to serve as a stem cell donor even in the absence of any family history of genetic disease.

The following could be asked: *Who is harmed by allowing PGD to be performed solely for the benefit of a relative?* Not the couple who wish to produce an embryo. Nor the child who would not otherwise have existed. Nor the person who receives the stem cell transplant that might save his or her life. It is argued that we must avoid the trap of interfering with individual liberty by preventing such procedures for no good reason, simply out of the 'genophobia' that grips much of society today.

Some people object to PGD, along with *in vitro* fertilisation, in any situation. Those who consider both procedures acceptable argue that it is reasonable to use them to bring a new person into the world *and* to help save an existing life.

However, uninhibited selection of children may threaten the very foundation of the parent-child relationship that must embody a strong element of unconditional love.

At present, there is no reliable way to assess whether any particular embryo will survive, especially in low prognosis IVF patients, so a positive outcome cannot be guaranteed.

DISCUSS:

Ethical questions remain around the creation of what are called 'designer babies' in order to treat a sibling.

A medical view

Genetic manipulation that is intended to be restorative, recreating a damaged length of DNA or replacing an abnormal gene variant with a normal counterpart, seems consistent with normal medical practice, but enhancing gene therapy can also attempt to improve on the original design.

In general, doctors have agreed that if no treatment is available then it is unethical to perform screening tests on apparently healthy people.

Further Reading:

Visit the (UK) Human Genetics Commission: www.hgc.gov.uk
Salvation Army Positional statements: www.salvationarmy.org.nz



A CHRISTIAN VIEW

C. S. Lewis said, 'Man's power over nature turns out to be power exercised by some men over other men.'

Human beings are far greater than the product of their genes. People who think that the embryo or foetus is a person will object to creating and destroying embryos and oppose most uses of PGD. Others believe that pre-implantation embryos are too rudimentary in development to have interests or rights, but that they still deserve special respect as the first stage toward a new person.

When does human life commence?

There are differing opinions:

- It happens at conception: the most common pro-life position
- It happens when blood first appears: a new interpretation viewed by some as biblical
- It happens later in pregnancy: the most common pro-choice position
- It happens at 14 or 22 weeks gestation: two novel arguments
- It happens during childbirth: the traditional Jewish position

Orthodox Christian thought has always affirmed that in the complex and mysterious unity that constitutes the human person, the physical structure of the body and the immaterial spiritual aspects of our being are important and inextricably entwined.

We are created in God's image, contaminated by evil, yet confirmed and redeemed by Christ. Accordingly, the sanctity of life is not just some kind of abstract obscure principle. A life is a life and every life can be filled with all kinds of positive things and real happiness. As well, we have a unique relationship with God who calls us into existence and into fellowship with him.

We also have a responsibility to protect, nurture, educate and respect our children, who are similarly created in God's image.

Are there alternatives?

Some at-risk couples have conceived and then undergone prenatal testing. If the result was positive, they then had the option of terminating the pregnancy. A difficult choice.

Instead of promoting ante-natal screening, should we be ensuring better provision of welfare services and financial benefits to parents of disabled children in order to make it easier for parents to decide to continue such a pregnancy?

Vigilance is vital

There is no doubt that PGD can lead to a 'Lego kit' mentality about humankind. *Christians must continually challenge this reductionist view!* We need to remain vigilant about the economic and political powerbase that new genetic technology is creating and demand democratic accountability, transparency and justice in the actions of those who control this technology.

DISCUSS:

We need to present a biblical worldview to society that regards human beings as wonderful but flawed masterpieces rather than randomly-generated, self-replicating organisms. This is a worldview that encompasses wonder, respect, empathy and protection for the weak and vulnerable in our society.

M.A.S.I.C.

Background

The Moral and Social Issues (Ethics) Council (MASIC) studies and formulates Salvation Army responses on significant moral, religious and social issues. Its aim is to help The Salvation Army New Zealand, Fiji and Tonga Territory take a proactive stance in relation to such issues, and to support Salvationist decision-making in everyday life.

MASIC 'Living Counter Culturally' Talk Sheets are intended as Internal Discussion and Resource documents for Salvationists. They provide biblical and theological reflection on the intersection of faith in the everyday world.

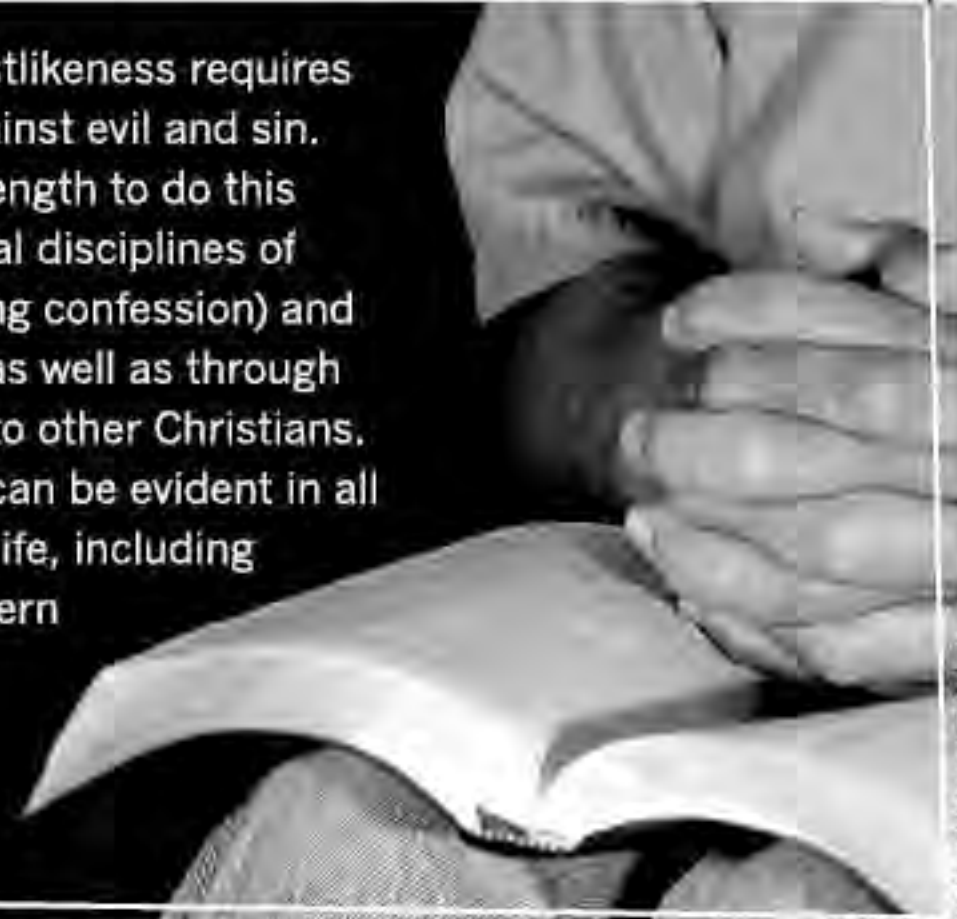
The 'Ethical Life'

The 'ethical life' is the Christ-like life. Through Jesus' incarnation, death and resurrection, our broken relationship with God is restored. We are then able to grow more and more like Christ, our Saviour and Lord. His words and example and the teaching of the Bible help us in this journey.

Growth in Christlikeness is expressed in the integrity of our character (who we are), in our ethics (the choices we make) and in our lifestyle (our actions). We live a Christ-like ethical life in our everyday activities when there is a clear synergy between the leading of the Holy Spirit and our own choices:

'Since we live by the Spirit, let us keep in step with the Spirit.' (Galatians 5:25)

Growth in Christlikeness requires us to stand against evil and sin. We find the strength to do this through spiritual disciplines of prayer (including confession) and Bible reading, as well as through accountability to other Christians. Christlikeness can be evident in all aspects of our life, including our social concern for others.



FOR MORE INFO:

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