

Education-Family Physician Corner

Preimplantation Genetic Diagnosis Ethical Aspects

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In vitro fertilization (IVF), certain genetic abnormalities in embryos could be diagnosed by the technique of Preimplantation Genetic Diagnosis (PGD) prior to implantation. The technique is used at the six to eight cell stage of embryonic development. Through polymerase chain reaction, the cellular DNA is tested for chromosomal abnormalities or genetic mutations. However, ethics provides norms for conduct that distinguish between acceptable and unacceptable behavior; the four general principles within what is called 'Principlism'. People involved in health care are expected to apply these general principles to particular situations to determine what is morally recommended.

Selection is an individual right. The freedom to make reproductive decisions is recognized as a fundamental moral and legal right that should not be denied to any couple, unless an exercise of that right would lead to harming themselves or others or it involve gender discrimination.

PGD is a mean to provide parents with the security that their children will be having the best possible start in the world. PGD would avoid the sufferings of offspring and extended family when a severely disabled child is born.

Doctors should promote the well-being of others. PGD is an extension of the doctor's duty of beneficence, working towards avoiding diseases and recurrent miscarriage.

PGD process is cost effective when one considers the cost compared with lifetime treatment for a single patient suffering from hereditary diseases.

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Advances in medicine and science, particularly in rerogenetics, mean that intending parents who may have particular difficulties in conceiving a child have a much wider range of choices to assist fertility but also to prevent transmission of hereditary diseases. In the past, options were limited to parents, but to accept nature and the genetic lottery. They did not have a choice to avoid conception of a diseased or severely disabled child, something now possible with IVF and PGD. Because couples did not have these possibilities, they could not make a choice to terminate an affected pregnancy. Assisted reproductive technology offers parents the security that their children will be more likely to have the best possible start in the world and might avoid the problems that could seriously affect their well-being¹. PGD is a technique based on IVF. After the creation of the embryo, the eight-cell embryos are genetically analyzed and only the healthy selected embryo is implanted in the mother's

uterus². People involved in health care are expected to apply general medical ethics to these particular situations and determine what is morally recommended.

UTILITARIAN AND DEONTOLOGICAL THEORIES

Utilitarianism is a moral viewpoint that is primarily concerned with the consequences of a proposed action. The moral good is whatever furthers the greatest happiness of the greatest number. The aim is to advance the good. Using Utilitarian principles, PGD must be morally evaluated in terms of whether it promotes a better society and also promotes the best interest of any resulting child. People are free to do whatever they want so long as it does no harm. The justification of PGD is essentially utilitarian appealing to the claimed benefits for prospective parents, i.e., starting a pregnancy with the single aim of producing a healthy child and human leukocyte antigen (HLA) compatible. Life according to the alternative moral viewpoint of deontology, it is wrong to choose an offspring for specific traits of an embryo no matter how well intentioned. Consequentialists received criticisms as being prepared to move towards eugenics where potential children will be valued for their genotype more than for their inherent characteristics as human beings³. According to Kant, a child should be respected as a being and end in itself, not as a means to a further end⁴.

REPRODUCTIVE AUTONOMY

This principle refers to a commitment to respect a person's decision about their health care. For example, if a person is in a situation where they understand all the relevant information and possible treatments and likely consequences of not having treatment, then they should be able to make their own decision about whether or not to accept a proposed treatment. The freedom to make reproductive decisions is recognized as a fundamental moral and legal right that should not be denied to any couple, unless an exercise of that right would lead to harming themselves or others.

There are many ethical aspects which stem from the application of reproductive control in women's health. This control can be improved if given the opportunity to make their own reproductive choices about the application of reproductive technologies⁵. Having the option to use PGD and the general principle of procreative autonomy should not be interfered with a woman's choice about procreation. Likewise, it is claimed that a couple's decisions about what is best for their children should be within the autonomous choices of parents unless, of course, these choices will cause harm to the children. Many commentators would argue that women and couples should have freedom in their procreative choices because there is no harm to the child. Advances in technology have preoccupied bioethicists in their attempt to judge our moral responsibilities and obligations when making reproductive decisions⁶. But it is debatable that woman should be free and accept her autonomy in decision-making because she will live with the consequences of those decisions.

BENEFICENCE

It is a moral obligation to act for the benefit of others and prevent the loss or damage to others. PGD is an extension of the doctor's duty of beneficence, working towards avoiding diseases and recurrent miscarriage. Making PGD available for couples was never a decision taken lightly. It was not about creating designer⁶. The potential benefits of PGD must be balanced against the risks of the proposed technique. PGD has been shown to improve assisted reproduction outcomes for targeted genetic anomalies. Apart from an increase in

resulting successful pregnancies following treatment, PGD also significantly reduces the risk of aneuploidy and miscarriage rates in a high risk groups. To date, there are no reports of increased identifiable problems such as fetal malformations and others that might be attributable to the embryo biopsy.

NON-MALEFICENCE

The principle of non-maleficence confers an obligation not to inflict harm on to others. It includes some of specific rules such as do not kill, do not cause pain or suffering and do not deprive others of the fundamental goods of life⁷. PGD is a means to provide parents with the security that their children will have the best possible start in the world. However, PGD is primarily indicated in situations where there is a high risk that the couple's offspring will suffer from a serious hereditary disease. Many arguments are put forward claiming that using PGD in this way is more human than allowing the embryo to die at a very early stage just a few days after fertilization. It is also more ethical than the option of ending the life of fully developed fetus in the third or fourth month of pregnancy. The latter situation would cause more emotional harm to parents, and could cause more physical harm to the unborn. In discussing their choice of PGD, parents often explain their fears that caring for a disabled child will take much of their time and responsibilities and so limit the time available to care for other children in the family.

Because there is concern about long-term effects of PGD, the UK Human Fertilization and Embryology Authority (HFEA) reviewed the safety evidence and concluded that embryo biopsy and PGD are safe.

JUSTICE

The principle of justice requires an equitable distribution of scarce resources and the benefits, as well as the burden associated with PGD. Justice also means respecting the couple's right. The autonomous choice of PGD is most often made so that their offspring will not suffer from a serious and debilitating genetic disease. However, the HFEA's decision to license tissue typing PGD may create pressure to expand PGD coverage under the National Health Service. The tissue typing in the PGD process is cost effective compared to lifetime treatment for a single patient suffering from hereditary diseases.

There are some who object to advances in assisted reproduction on the grounds that we have overstepped our boundaries in human research, which should remain under the control of God. If life is given by God, human should not determine who lives, survives and with what quality. This argument promotes the view that procreation should only be done in the way God intended, which is through sexual intercourse.

Another central concern states that PGD discriminates against people with disabilities. This concern is voiced by some disabled persons who claim that persons already living with mental or physical disabilities will be stigmatized when PGD becomes a viable and widespread option to prevent disabled infants from being born. On these grounds, it should be prohibited or at least reviewed for its social effects⁸.

Other concern is that selection by PGD is eugenic practice, which controls the quality of the human race by pre-selecting certain traits. However, others argue that it is a mistake to equate informed and free individual choices with the ideology and practice of eugenics⁹.

The term ‘Savior Sibling’ refers to an offspring selected through PGD who will be able to provide stem cells to a suffering sibling and a chance of a healthy life. The main argument against allowing the deliberate creation of savior siblings are commodification of babies, long-term psychological welfare of the child born to be the savior sibling; he/she might be threatened if they feel they have been instrumentalized and not loved for themselves by being born to help an ill sibling. There are genuine fears of the slippery slope and moving towards designer babies.

CONCLUSION

The utilitarian sees autonomy and liberty as bringing a good outcome. Their view is that the individual should have the right to make decisions for themselves in all matters unless these decisions cause significant detrimental harm for others. Keeping this harm principle in mind, people are encouraged to make the decision about their reproductive life. PGD is primarily used to satisfy some morally acceptable preferences of potential parents. Specifically, they may have a strong preference for a non-disabled child because they fear that caring for a disabled child would be too arduous.

The inherited hemoglobinopathies are a group of disorders that include thalassemias and sickle-cell disease; these diseases are a major public health problem in Bahrain. Although the numbers of affected children born with genetic diseases have been reduced in recent times, it is still considered a major public health problem. Management of these disorders incurs a high financial cost and it is a great burden on the healthcare system and the family. PGD should be ethically permitted for:

- a) High risk couples who would be expected to have children with serious genetical diseases.**
- b) The probability of late onset diseases.**
- c) Those with a high frequency of consanguineous marriages where the family has a history of severe congenital and hereditary disease, PGD can help reduce the incidence of genetic diseases in such circumstances.**

In practice during premarital counselling, we still see couples who are at risk of having children with hereditary disease and yet persist in wanting to marry. The couples at risk are referred to the genetic clinic for further advice and management; those couples should be offered PGD. Preimplantation Genetic Diagnosis is cost effective, because the lifetime treatment for a single patient suffering from beta thalassemia or Sickle cell disease is much more than PGD.

Potential conflicts of interest: None.

Competing interest: None. **Sponsorship:** None.

Submission date: 22 July 2014. **Acceptance date:** 15 November 2014.

REFERENCES

1. Maclean S. Modern Dilemmas: Choosing Children. Edinburgh: Capercaillie Books, 2006: 157-8.

2. Human Fertilization Embryology Authority, Human Genetic commissions. Outcome of the Public Consultation on Preimplantation Genetic Diagnosis. Available at: http://www.hfea.gov.uk/cps/rde/xbcr/hfea/PGD_outcome.pdf. Accessed on 22.9.2014.
3. Robertson JA. Extending Preimplantation Genetic Diagnosis: The Ethical Debate. Ethical Issues in New Uses of Preimplantation Genetic Diagnosis. *Hum Reprod* 2003; 18(3):465-71.
4. Drebusenko DW. Creating Children to Save Siblings' Lives: A Case Study for Kantian Ethics. In: Humber J, Almeder, R, eds. *Biomedical ethics reviews*. New Jersey: Humana Press, 1991: 89-101.
5. Schenker JG. Gender Selection: Cultural and Religious Perspectives. *J Assist Reprod Genet* 2002; 19(9):400-10.
6. Human fertilisation and Embryology Authority. Ethics & Law Advisory Committee. Available at: http://www.hfea.gov.uk/docs/2009-12-15_ELAC_-_Case_by_case_decision_making_in_PGD_-_Paper.PDF. Accessed on 22.9.2014.
7. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. New York: Oxford University Press, 2001: 85.
8. Stainton T. Missing the Forest for the Trees? A Disability Rights Take on Genetics. *Disabilities* 2007; 13(2):89-92.
9. Savulescu J. Procreative Beneficence: Why we should Select the Best Children. *Bioethics* 2001; 15(5-6):413-26.