

# Preimplantation Genetics Diagnosis: Ethical and Legal Aspects

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**Abstract**---Preimplantation genetic diagnosis (PGD) is an important method for the identification chromosomal abnormalities and genes responsible for genetic defects in embryos that are created through in vitro fertilization before pregnancy. This technique can screen sex and genetic abnormalities to avoid the implantation of defective embryos. However, PGD can potentially raises ethical issues such as the embryos deselection, sex selection, savior siblings, and eugenics. PGD is used to select the best embryos in terms of genetic profiles. This raises the potential of embryos that are not either discarded or donated to science. This selection discriminates people with disabilities. It also poses a dilemma in view of the Hippocratic oath that every doctor should value life from conception. PGD can find out the sex and diseases that may be related (X-linked disorder), so often there is a demand to change sex so that the embryo is not affected by the disease. The problem is if the demand by parents who want a child of a certain sex as family balancing. PGD is also used to save siblings (savior siblings). PGD is only for screening for serious genetic diseases, but has the potential to develop into modern eugenics that design children as desired, such as gender, height, beauty, intelligence, and hearing; according to the demands of parents who want the best for their children Regulation and further studies from various disciplines are needed to prevent potential ethical and legal problems.

**Keywords:** PGD (Pre-implantation genetic diagnosis), IVF (In vitro fertilization), ethics, legal aspects

## I. INTRODUCTION

Technology comes with the aim of 'rehumanize', humanizing humans and creating the best quality of life for humans by minimizing suffering and increasing life expectancy either through promotive, preventive, curative, or rehabilitative methods.

IVF or in vitro fertilization (IVF) is a health technology in the field of reproduction that is in line with human rights to have offspring. IVF technique is an in vitro fertilization technique, where the ovum is fertilized outside a woman's body. This technology was first successfully practiced in 1970, starting with the discovery of sperm-preserving techniques in liquid nitrogen at a temperature of -321 degrees Fahrenheit.

With this technology, infertile couples have the hope to have offspring that remain from their seeds. In line with the development of reproductive technology, society is now beginning to be oriented towards getting healthy children, one of which is through prenatal diagnosis. Identification of fetal defects from the womb through ultrasound or amniocentesis procedures have begun to be developed. This can be polemic if a defect is found in the child conceived, will it continue to live or be otherwise aborted.

Pre-implantation genetic diagnosis (PGD) appears to overcome the polemic. PGD was developed to determine the genetic profile of the embryo so that selection can be made before implantation so that it is considered more human. This technique is often aimed at avoiding children with birth defects from at-risk parents in IVF or in vitro fertilization (IVF) programs.

However, besides providing convenience, PGD has the potential to cause polemics and dilemmas in the field of ethics. Changes in the concept of the definition of child, the perfection of the child as God's creation, the meaning of pregnancy, childbirth, and the purity of life that focus on human production are possible risks. Other problems such as sex selection, embryonic buying and selling, and eugenics are also at risk of developing

## II. LITERATURE REVIEW

In Vitro Fertilization is an assisted reproductive technology (ART) commonly referred to as IVF. IVF is the process of fertilization by extracting eggs, retrieving a sperm sample, and then manually combining an egg and sperm in a laboratory dish. The embryo(s) is then transferred to the uterus. Other forms of ART include gamete intrafallopian transfer (GIFT) and zygote intrafallopian transfer (ZIFT).

There are five basic steps in the IVF and embryo transfer process:

Step 1: Fertility medications are prescribed to stimulate egg production. Multiple eggs are desired because some eggs will not develop or fertilize after retrieval. A transvaginal ultrasound is used to examine the ovaries, and blood test samples are taken to check hormone levels.

Step 2: Eggs are retrieved through a minor surgical procedure that uses ultrasound imaging to guide a hollow needle through the pelvic cavity to remove the eggs. Medication is provided to reduce and remove potential discomfort.

Step 3: The male is asked to produce a sample of sperm, which is prepared for combining with the eggs.

Step 4: In a process called insemination, the sperm and eggs are mixed together and stored in a laboratory dish to encourage fertilization. In some cases where there is a lower probability of fertilization, intracytoplasmic sperm injection (ICSI) may be used. Through this procedure, a single sperm is injected directly into the egg in an attempt to achieve fertilization. The eggs are monitored to confirm that fertilization and cell division are taking place. Once this occurs, the fertilized eggs are considered embryos.

Step 5: The embryos are usually transferred into the woman's uterus three to five days following egg retrieval and fertilization. A catheter or small tube is inserted into the uterus to transfer the embryos. This procedure is painless for most women, although some may experience mild cramping. If the procedure is successful, implantation typically occurs around six to ten days following egg retrieval.

Preimplantation genetic diagnosis (PGD) is a procedure used prior to implantation to help identify genetic defects within embryos. This serves to prevent certain genetic diseases or disorders from being passed on to the child. The embryos used in PGD are usually created during the process of in vitro fertilization (IVF). A preimplantation genetic diagnosis can benefit any couple at risk for passing on a genetic disease or condition.

Preimplantation genetic diagnosis begins with the normal process of in vitro fertilization that includes egg retrieval and fertilization in a laboratory. Over the next three to five days, the embryos will divide into multiple cells.

Preimplantation genetic diagnosis involves the following steps. First, a couple/few cells are microsurgically removed from the embryos, which are about 5 days developed. After this cell collection, the embryos are safely frozen. The DNA of the cells is then evaluated to determine if the inheritance of a problematic gene is present in each embryo. This process takes at least one full week. Once PGD has identified embryos free of genetic problems, the embryo(s) will be placed in the uterus (usually by an IVF procedure), and the wait for implantation and a positive pregnancy test begins. Any additional embryos that are free of genetic problems are kept frozen for possible later use while embryos with the problematic gene(s) are destroyed. This testing process may take weeks.

Getting from the egg retrieval process to the final results of PGD can take several weeks. This process includes collection, fertilization, 3-5 days of development, 1-2 weeks of testing, and scheduling an appointment to discuss results.

There are the type of individuals who are possible candidates for PGD: Carriers of sex-linked genetic disorders, carriers of single-gene disorders, those with chromosomal disorders, women age 35 and over, women experiencing recurrent pregnancy loss, women with more than one failed fertility treatment.

Some of the goals of PGD include:

1) Monogenic Disorder

At present, PGD is widely used for monogenic disorders, namely chromosomal disorders due to a single gene (autosomal recessive, autosomal dominant or X-linked). PGD will identify embryos carrying genetic diseases or chromosomal abnormalities, in order to avoid the birth of a sick child. The most commonly diagnosed autosomal recessive disorders are cystic fibrosis, beta thalassemia, sickle cell disease, and type 1 spinal muscular atrophy. The most common dominant autosomal diseases are dystrophy myotonia, Huntington's disease, and Charcot-Marie-Tooth disease, while cases associated with the X chromosome are hemophilia A and Duchenne muscular dystrophy. PGD is also now being done for hereditary multiple exostoses (MHE / MO / HME). In addition, there is a gene carrier pair choosing PGD because it can be easily combined with IVF treatment.

2) Determination of Pregnancy Opportunities

PGD has been suggested as a method for determining the quality of fertilized embryos in vitro, to select embryos that appear to have the greatest chance of successful pregnancy. However, because it relies on a single cell assessment, PGD has limitations because it is random in nature which may not represent the embryo.

3) Savior siblings

Savior siblings are children who are deliberately born to provide organ or tissue donors to be transplanted to their former siblings who suffer from diseases such as thalassemia- $\beta$  or Fanconi anemia. In transplants, the compatibility of the human leucocyte antigen (HLA) between the donor and the recipient is important. HLA can be known since it is still in the form of an embryo. PGD can select embryos that have the same HLA as recipients and are free of genetic diseases and will then be implanted in the uterus during IVF. The best transplant is done with a hematopoietic stem cell transplant obtained from the umbilical cord of the recipient's fetus being born.

4) Gender Identification and Selection

PGD can find out the sex of the embryo even before implantation. There are 42 percent of clinics offering PGD had provided gender selection for non-medical reasons. Nearly half of them do it just to "balance the sex of the family," that is, if a couple of two or more children wants one child of the other sex.

### III. FINDINGS AND DISCUSSION

In Law No. 23/1992 on Health article 16 paragraph 1 it is written that pregnancy outside the natural way can be

implemented as a last resort to help husband and wife get offspring. In paragraph two the pregnancy attempt outlined in a natural manner as referred to in paragraph one can only be made by a legitimate married couple with several provisions.

These provisions are the result of fertilization of sperm and ova from the husband and wife concerned, implanted in the womb of the wife from where the ova originated; carried out by health workers who have the expertise and authority to do so; and in certain health facilities. In paragraph three, it is written that the provisions regarding the requirements for administering pregnancy outside the natural way referred to in paragraph 1 and paragraph 2 are stipulated by Government Regulation.

Even after Law No. 23/1992 was revised into Law NO 36/2009, it was still emphasized in article 1 that pregnancy efforts outside the natural way can only be done by a legitimate married couple with the provisions of the sperm and ovum fertilization results from the husband and wife concerned implanted in wife's uterus where the ovum came from; carried out by health workers who have the expertise and authority to do so; and in certain health service facilities.

The assertion of sperm in the test tube baby must come from the husband also stated in Government Regulation No. 61/2014 on Reproductive Health. Article 40 paragraph 1 states that Reproduction with Assistance or Pregnancy outside the Natural Way can only be carried out on married couples who are bound by a legal marriage and experience infertility or infertility to obtain offspring.

In paragraph 2 also said Reproduction with Assistance or Pregnancy Outside the Natural Way referred to in paragraph 1 is carried out using the results of fertilization of sperm and ovum originating from the husband and wife concerned and implanted in the womb of the wife from which the ovum originated.

PGD technology has the potential to cause various ethical problems, including:

#### 1) Embryo Selection

PGD is used to select the best embryos in terms of genetic profile. This raises the potential of embryos that are not either discarded or donated to science. This selection discriminates people with disabilities. It also raises a dilemma if you look at the Hippocratic oath that every doctor should respect life since conception, and the Indonesian Medical Code of Ethic sexplanation in 2011 article 11 that humans since conception have the right to life.

The use of unused embryos as research samples is permitted with certain conditions. The International Islamic Center for Population Studies and Research, International Federation of Gynecology and Obstetrics (FIGO), and Guidelines for IVF Services in Hospitals, Directorates of Special and Private Hospitals, Ministry of Health of the Republic of Indonesia permits the use of embryos for the study of no more than 14 post-fertilization day.

#### 2) Sex Selection

PGD can find out the sex and diseases that may be related (X-linked disorder), so often there is a demand to change sex so that the embryo is not affected by the disease. According to FIGO, sex selection to avoid inherited diseases is permissible. The problem is if the demand by parents who want a child of a certain sex as family balancing. In 2000 in Italy, Alan and Louise Masterton registered with the HFEA (Human Fertilization and Embryology Authority) to request permission to undertake a PGD in order to get a baby girl after her daughter's death due to an accident. The couple already have 4 sons and Mrs. Masterton had been sterilizing after the fifth session. HFEA allows, but it turns out the three embryos used failed. In the UK, the use of PGD for family balancing is prohibited by law. In China and India, sex selection is a potential trade, given that in both countries parents often prefer children with male sex. In Indonesia there are no regulations governing this matter.

#### 3) Savior Siblings

PGD is also used to save siblings (savior siblings). In August 2002, someone asked permission from HFEA to do IVF using PGD so that the resulting embryo could save his child who had Diamond BlackfanAnemia (DBA). The embryo that develops into a fetus will have its stem cells taken for transplantation after adjusting to its siblings. A survey of 4000 Americans showed that 61% of them accepted the use of PGD for the purpose of saving relatives. This raises ethical problems, there has been a shift in the meaning of pregnancy which is no longer a gift or a sacred thing from God, but as a production process whose results can be arranged according to the wishes of the producers. The psychological aspect of the child born is certainly something to watch out for, considering that the child was born to save his previous sibling after going through a strict selection of embryos with HLA (human leukocyte antigen) prerequisites and free from genetic diseases similar to those of his siblings.

#### 4) Designer Babies

At present, PGD is only for screening for serious genetic diseases, but has the potential to develop into modern eugenics that design designer babies as desired, such as gender, height, beauty, intelligence, and hearing; according to the demands of parents who want the best for their children. If PGD can produce perfect children, it is not impossible if later IVF and PGD are done not only based on indications, but based on demand. This is certainly unsettling and strict rules are needed.

#### IV. CONCLUSION

The use of PGD in IVF technology can lead to various ethical problems such as embryo selection, sex selection, savior siblings, and designer babies. Therefore, the government together with experts from various disciplines is expected to be able to establish regulations that are in accordance with existing technology, so that it does not cause ethical and legal problems in the future.

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