

Ethical issues in prenatal diagnosis and therapeutic abortion in Iran

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ABSTRACT

Prenatal Diagnosis (PND) is one of the most controversial and challenging issues in the modern medicine around the world. Different countries have a various approaches toward this intricate issue. Crosslinking between religion and medicine or health is explicit in this field; so various aspects should be considered in the policy and compliment of the rules for PND. In many cases, the most controversial issue after PND is deciding for therapeutic abortion. In some religions or cultures and countries, this action is completely forbidden; but in the others, parents can choose the pregnancy termination till the delivery or until special time of gestation. Because of the high rate of the consanguineous marriage in Iran (up to 60% in some areas) PND and therapeutic abortion is available and needed to prevent some inherited disorders.

In Iran; according to religion and believes, therapeutic abortion is only acceptable under special conditions that could be harmful for mother's health or considered threaten for her life. Also some severe conditions like mental and physical disabilities in fetus could leads to arranged termination of pregnancy. Therapeutic abortion for aforementioned conditions should be done before fetus ensoulment. These conditions should approved by Iran Legal Medicine organization. In this review, we will discuss all related issues. This will help other countries and similar cultures to implement such regulations for these conditions.

Keywords: Medical ethics, Prenatal diagnosis, Therapeutic abortion, Genetics.

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Introduction

Prenatal Diagnosis (PND) is a diagnosis of diseases or conditions in a fetus or embryo before it is born (1). The aim is to diagnose birth defects such as neural tube defect, Down syndrome, chromosomal abnormalities, inborn error of metabolism, genetic disease (2, 3). It can also be used for fetus sex determination before born (4). The objective of prenatal diagnosis is not only to

identify abnormalities in the fetus and to terminate the pregnancy if necessary, but to inform couples that risk giving birth to babies with genetic disorders as well as limitations and options available to them. A contentious debate in PND is abortion which considered as one of the most debating and controversial issues so far because of various reasons and negative mental impact on

mother (5). Different countries have a various approaches toward this intricate issue. Crosslinking between religion and medicine or health is explicit in this field; so various aspect should be considered in the policy and compliment of the rules for PND (6, 7).

Because of the high rate of the consanguineous marriage in Iran up to 60% in some areas, PND and therapeutic abortion is available and needed to prevent vital disorders (8). Consanguineous marriage, where couples are related as second cousins or are related closer. This type of marriage is considered a causative factor in the appearance of genetic disorders. Consanguinity is a vital subject of interest due to it's high risk factor in causing various health problems. It is also a common cultural practice in some countries around the world such as Iran (5, 9, 10).The most prevalent abnormalities because of consanguineous marriage are intellectual and developmental disabilities, hearing loss/impairment, and inborn error of metabolism (8).

In many countries abortion remains a highly contentious moral issue. Abortion is a highly argumentative ethical subject, with the argument usually framed as a combat between the fetus's right to life and the woman's right to select. In this principle, dispute does not seem to exist much option to negotiate. Furthermore, much of the disagreement to abortion is because of religious stimulation to guard the fetus, mainly among Roman Catholics, Orthodox Jews, and Muslims (11). Most proportion of experts, support abortion for fetuses with severe congenital diseases (12).

Pregnancy termination is a sensitive issue and appearance of complex moral contradictions and complications is unavoidable. Without the choice of PND and Preimplantation Genetic Diagnosis (PGD), couples with inherited diseases in their

families may be deprived from the blessing of having children (13).

PND happens in the first and second trimester of pregnancy frequently pointing at danger valuation for common aneuploidies and fetal abnormalities. Conventionally, the purpose of prenatal screening was to identify common trisomies such as Down syndrome, nevertheless other genetic disorders comprising neural tube defects, sickle cell anemia, cleft palate, cystic fibrosis, beta thalassemia, Tay Sachs disease, muscular dystrophy and fragile X syndrome, have progressively entered into the field of PND. This has been made practical with the arrival of novel genetic technologies that permit a broader set of genetically influenced circumstances to be distinguished on the DNA level. This has equally formed the ethically pertinent issues that have been connected with PND (14-17).

Since prenatal screening has potential for selective abortion which is an extremely delicate ethical issue in numerous countries, this constitutes the chief moral issue. Nevertheless, disability rights campaigners also remark the purpose of prenatal screening services as extremely worrying and having unfair effects because it supports the idea that lifetime with disability is slightly negative that can/should be evaded. The worldwide usage of prenatal screening is modest, but growing. PND is regularly used in the developed world, and it is better to be obtainable as a public health enterprises (18).

Abortions due to fetal abnormalities are less than 2% of a total of 200,000 abortions which take place every year in the UK. There are also reports of abuse for such services due to some individuals taking advantage, which is unavoidable though contrary to the law (19, 20). Technologies which may entail ethical issues include DNA microarray

techniques and automatic mutation detection. These techniques may provide the possibility of widespread genetic screening at a cheap price for PND (21). In some cases, parents want to be aware of their children carrying autosomal dominant diseases which occur in adulthood such as Huntington's disease. In such cases, it should be determined whether these findings will help parents lead their children to education and employment opportunities or will rejecting their demands be considered denial of their parental rights. In other cases, parents request information about the carrier status of healthy siblings of a child with recessive disorder such as cystic fibrosis. The problem with such requests is the abuse of the child's future autonomy. Tests must be delayed until the child reaches an age to make informed decisions. Also, if a child is aware of their illness from an early age, especially if their siblings are healthy, they may suffer detrimental effects such as the feeling of humiliation and frustration during their childhood. However, there is an agreement among human and medical genetic specialists that children should not be tested to determine their carrier status (22). The only case in which genetic testing on children is possible is when predictive tests may have beneficial medical effects for the children. This condition is met for issues such as familial hypercholesterolemia and phenylketonuria. In such situation, early monitoring of food consumption may be beneficial. Also, in some predisposing familial cancer syndromes, early treatment and preventive surgery can take place if there are early indications (22) such presymptomatic thyroidectomy in medullary thyroid cancer (23).

One of the reasons that forbidden genetic testing on children for detecting late onset disease, is parents biased towards their children. There is also a similar case for PGD where the embryo is

not only tested for Fanconi syndrome, but to potentially use stem cells for siblings who are patients. People who use this technology view children as tools or consumers. In addition, children who are created this way, have no idea about their tissue donation to their siblings (22, 24). PND and potentially subsequent pregnancy termination will cause many problems for families involved which includes vital questions concerning social treatment and care for disabled children and adults to arise. In England, abortion is permitted until the end of week 19 of pregnancy and any time beyond only if the fetus has a fatal condition such as encephalitis or serious physical or mental retardation. This decision depends on the severity of the patient's condition and parents who decides to terminate the pregnancy (12).

Single gene disorders are inherited in particular inheritance patterns and each one conveys a different recurrence risks. Number of PGD services carried out for single gene disorders is become more and more every year. More than twenty five years old after the first clinical application, PGD is a determined medical process and a known alternative to conventional PND for patients at high risk of conveying a genetic disorder to their child (25).

In fact, PGD represents an option to PND and provide a condition that permits selection of unaffected IVF embryos for starting healthy fetus pregnancies in couples at danger for conveying a genetic disorder (26). Today PGD established for clinical practice and performed for these types of diseases and conditions: single gene disorders, chromosomal rearrangements, Preimplantation genetic screening (PGS) and PGD-HLA (27).

In Iran, therapeutic abortion takes place upon the validation of three specialist doctors and legal medicine approval who decide whether the deformed fetus will cause hardship for the mother

or the mother's illness may be fatal or not. Termination may take place until month four of pregnancy with the mother's consent and without the doctor's responsibility. Violators of the provisions of this law will be sentenced according to Islamic law. The abortion law was approved by the Islamic Consultative Assembly as a single article in a public hearing in 2005 and later approved by the Guardian Council (28).

Therapeutic abortion indications in Iran

Iran's Legal Medicine organization article number 1/4176 dated in 2003:

1- Continuation of pregnancy in the cases that may be fatal to the fetus or mother, a request for therapeutic abortion (only from Legal medicine main offices) will be accepted upon validation from a judicial authority and the treating doctor before month four of pregnancy.

2- The physician referral should include the patient's photograph (stamped by doctor), identification characteristics to validate identification, patient's diagnosis and diagnosis method (symptoms and paraclinical tests) with attached photo identification and authentication documents of the couples involved along with paraclinical tests (with patient's stamped photo and identification characteristics).

3- For fetal indications, at least two ultrasonographies for maternal indications, one ultrasonography for pregnancy age and a physician's referral letter are required.

4- At least two expert advice letters must be attached to the physician's referral letter as diagnosis validation. In cases other than indications, presentation of at least three expert advice letters based on abnormalities that are fatal for fetus or risks of maternal death are necessary.

Abortion indications for maternal diseases

Heart:

1-Any valve related disease that can lead to heart failure functional class 3 and 4 and irreversible to functional class 2.

2-Any acute coronary complications apart from coronary artery with functional class 3 and 4 such as myocarditis and pericarditis.

3-Dilated cardiomyopathy history for previous pregnancies

4-If the diameter of the ascending aorta in the case of Marfan syndrome is over 5cm

5-Eisenmenger syndrome

Digestion:

1- Pregnancy fatty liver

2- Esophageal varices

3- History of esophageal varices bleeding followed by portal hypertension

4- Nephrology uncontrollable autoimmune hepatitis: 1. Kidney failure 2. Uncontrollable blood pressure using authorized agents during pregnancy

Lungs:

Lung diseases; such as emphysema, fibrosis, scoliosis and bronchiectasis that cause pulmonary hypertension even in mild cases.

Hematology:

Coagulopathies with prescribed heparin, that leads to other maternal life threatening diseases.

Infectious:

HIV virus infection which has entered the AIDS disease stage.

Rheumatology:

1-Uncontrollable active lupus involving a major organ

2-Vasculitis involving major organs

Neurosurgery:

Types and places of origin for all space-consuming CNS masses must be considered when fetus treatment and lack of treatment for the mother may be fatal.

Skin:

Pemphigus vulgaris, severe and general psoriasis and advanced melanoma which cause a serious risk to the mother's life.

Neurology:

- 1- Epilepsies that resist despite multi-drug treatment
- 2- Multiple Sclerosis diseases that handicap or disable patients
- 3- Myasthenia gravis disease at advanced stages which may be fatal for the mother
- 4- Various motor neuron diseases that are aggravated by pregnancy and endanger the mother's life.

Abortion and fetal abnormalities indications in patients with intrauterine fetal death and fetal or neonatal death soon after birth include:

Surgery and orthopedics:

Bilateral renal agenesis, recessive polycystic kidney, renal cystic dysplasia, potter syndrome, congenital nephritic syndrome that causes hydrops, chromosome abnormalities which cause inflammation specially involving the brain and kidneys such as VACTERL association (also VATER association) and severe bilateral hydronephrosis.

Hematology:

Alpha thalassemia in the form of hydrops fetalis

Infants:

- 1- Trisomy 13,16, and 18,
- 2- Anencephaly
- 3- Hydrops fetalis with any mechanism
- 4- Cat cry syndrome
- 5- Holoprosencephaly
- 6- Sirenomelia
- 7- Cranioschisis
- 8- Meningoencephalitis, meningoencephalitis hydrocephalus
- 9- Thanatophoric dysplasia or neonatal lethal dwarfism
- 10- Cyclobia with holoprosencephaly
- 11- Congenital ichthyosis
- 12- Schizencephaly
- 13- Anencephaly (29)

In addition to the cases mentioned above where abortion certificate is issued, there are still some diseases that provoke challenges.

Autonomy and individual choices when infants are impaired relatively mild in some examples such as cleft lip or palate with optimal surgery available along with newer methods for promoting higher quality of treatment, certain dilemmas appear (30). For parents, especially those who experienced similar complications during their childhood along with the embarrassment of suffering from such impairments, having such children is unacceptable. The medical community does not agree with such requests for pregnancy termination and various criteria including legal, religious and social aspects have profound influence in decision making under these conditions in different communities.

Conclusion

Ethical issues are of great importance in medical genetics, especially ethics in perinatal genetics is an indispensable dimension (31). Due to the ever

increasing advances in medical genetics and innovation on genetics diagnostic methods, awareness on human genome is increasing and new unknown genes associated with human diseases are discovered which entail new responsibilities along with legal and ethical issues. Individuals are concerned with the exposure of their genetic information which increases the possibility of abuse and threatens the security of some people's lives. Specifically, the medical genetics community plays a key role in balancing the needs of patients and families and ethical issues. Effective performance of medical geneticists may enable advances in diagnostic and therapeutic procedures while ensuring the safety and privacy of patients by keeping their medical information confidential. Nevertheless, medical genetics is not able to respond to ethical issues and dilemmas alone, and problems will be encountered in different societies with different cultures, beliefs and religions must be addressed accordingly. Responsibilities of medical geneticists are increasing to ensure the interests of patients and families (32).

Conflict of Interest

The authors declare no conflict of interest.

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