



ETHICAL ISSUES of PRENATAL DIAGNOSIS in TURKEY

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Introduction

Prenatal diagnosis is a procedure which is testing fetus for various diseases (chromosomal and single gene defects) and congenital abnormalities according to week of pregnancy with appropriate methods. prenatal diagnosis provides treatments before birth if it's possible, post natal precautions and cure planning. if any congenital defect detected with those methods, parents can go for terminating pregnancy. prenatal diagnosis employs a variety of invasive and non-invasive techniques to determine the health and condition of an unborn fetus. These techniques are ultrasonography, chorionic villus sampling, fetal blood cells in maternal blood, maternal serum alpha-fetoprotein, maternal serum beta-HCG, maternal serum estriol. prenatal genetic tests are divided as cytogenetic tests and molecular tests.

Genetic counselling for prenatal diagnosis informs parents whom face with prenatal problems and defects and affecting results. Obstetrician directs parents to genetic counselling if there is a risk for wrongful births and lifes. The informer should be a genetic specialist or physician, biologists, psychologist whom are educated for genetic counselling. The genetic counselling is described as informing the patients in an understandable manner about the genetic disorder risks they may face, and the process which is caused by these risks with a patient oriented approach without manipulating. Genetic counselling for prenatal diagnosis informs parents whom face with prenatal problems and defects and affecting results.

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Prenatal Diagnosis in Turkey

All around the World amniocenteses is a procedure applied over 100 years. In Turkey, prenatal diagnosis for chromosomal abnormalities are studied about 40 years. When prenatal genetic diagnosis are implemented for 40-45 years, in Turkey it is practised for last 25 years. In Istanbul University Institution of PRETAM (prenatal diagnosis Center) 2000-3000 parents get genetic counselling and 700-1000 pregnant are examine with invasive prenatal diagnosis methods per year. Beside that government health centers, there are some private prenatal diagnosis centers. But the number of couple who apply to this method is still less. Among the reasons of it, ignorance, fear, misinformation, beliefs come first.

Table 1. Methods of prenatal diagnosis.

Methods	Procedure	Advantages and Risks
Chorionic Villous Sampling	Transcervical or transabdominal aspiration of trophoblastic tissue for karyotyping and genetic studies in pregnancies less than nine weeks.	Early diagnosis and timely termination of pregnancy 3 % abortion risk.
Genetic Amniocentesis	Aspiration of amniotic fluid under ultrasound guidance and culture and karyotyping of amniotic cells. Early <11 weeks; Late -16-18 weeks.	Early diagnosis and timely termination of pregnancy 3 % abortion risk.
Routine Ultrasonography	Performed at 16-18 weeks or earlier to diagnose structural anomalies of the early embryo-fetus.	Allows second trimester termination of pregnancy.
Precutaneous umbilical blood sampling	PUBS refers to transabdominal aspiration of fetal blood from the umbilical vein for detailed analysis of fetal diseases by performing hematological, genetic, immunological etc fetal diseases.	Allows the diagnosis of numerous fetal diseases

Ethical and Legal Aspects of Prenatal Diagnosis in Turkey

With wrong methodology and wrong interpretation of prenatal genetic tests or any negligence may cause harm or loss of fetus. Since 40-45 years in USA, prenatal genetic tests have been applied and physicians must inform accurately parents about prenatal genetic tests. For example, it is a crime not to offer prenatal diagnosis to a 35 year-old pregnant. Anybody can't force physician to practise any kind of invasive methods such as CVS, AS, KS. Frankly, most of them aren't qualified and it's a malpractise for them to apply methods. Physicians can reject practising methods if these methods doesn't fit to their moral values. But they have to direct patients to genetic counseling. Physicians can be against to abortion, sterilization or birth control or support. But they can't impose their thoughts to patients. Data which obtained from these methods can't be transferred to any others (insurance agents, employer, school). In Turkey, detection of harm occurrence resulting from prenatal diagnosis and through legislation for punishment process limits are not clear. In our country, there is no legal regulations for prenatal diagnosis. This type of cases are concluded due to expert-witness reports. In the 6th article of Ministry of Health, the Guidelines of Genetic Diseases' diagnosis Centers «Which tests are going to be performed in prenatal diagnosis are advised by Genetic Diseases' Scientific Committee and assigned by Ministry.» inscription is mentioned. However, without consent of patients none of tests could be applied unless there is a situation that risk public health. Then why prenatal diagnosis is an uncommon method compared to the others. In Turkey there are competent obstetricians give informations to parents about prenatal diagnosis and direct them to genetic counselling. Especially for parent lack of knowledge about prenatal diagnosis process and procedures. If prenatal diagnosis goes wrong, the mistaken advice may lead to a false assurance that the fetus is not at risk of a congenital abnormality (e.g. Down syndrome, sickle cell anemia etc.) and maybe holding back parents from opportunity of terminating the pregnancy and vice versa. In this circumstances genetic counselor should talk about risk when evaluating and explaining the results. If genetic counselor does not inform parents or not mentioning about the risk this situation is malpractise.

Results and Discussion

All pregnant women have right to take prenatal diagnosis. But if ethical considerations come first, this rights can be restricted. For example, the decision to terminate the pregnancy depending on the test results does not belong to the parents. The obstacles in the implementation of unilateral decisions taken, the patients, physicians and the fetus have rights to create their own base. Decision on someone's life can cause critical ethical debate. This discussion about age, gender, race, intelligence and physical disability discrimination; prenatal diagnosis is made for the benefit of whom; on how equitable cost calculations are made.

To eliminate these ethical concerns;

1. Each couple need to be clarified in detail about the importance, benefits, potential losses and risks of prenatal diagnosis.
2. Prenatal diagnosis should be offered in the light of current scientific development.
3. Prenatal diagnosis should be planned starting from non-invasive tests.
4. Invasive prenatal diagnosis tests should be offered in accordance with the choice of couple, non-invasive test results and the circumstances of parents.
5. Genetic counseling shouldn't be manipulating. Final decision always belongs to the parents.

In conclusion, starting ethical debate with The Human Genome Project, in November 1997 a conference (29th general conference) was organized by United Nations Educational, Scientific, and Cultural Organization (UNESCO) and 'Universal Declaration on the Human Genome and Human Rights' was published one year later. The declaration has been cited in many academic and popular journals and has been referred to in numerous national and regional legislation on medicine, privacy and genetic research. The absence of such an arrangement in Turkey is still a problem to be solved urgently. To this end, a commission should set up composed of competent scientists and lawyers and the legislation needs to be done.

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