

NATIONAL BIOETHICS COMMISSION

OPINION

ON PRENATAL AND PRE-IMPLANTATION DIAGNOSIS AND EMBRYO TREATMENT

The National Bioethics Commission met upon invitation by the President thereof on 3.11.2006, 1.12.2006, 2.2.2007, 29.3.2007 and organized a hearing on 9.3.2007 with the experts Emmanuel Kanavakes, Professor of Paediatrics at the University of Athens and Demetris Loukopoulos, Professor Emeritus of Pathology at the University of Athens, in order to consider the ethical and social issues within its jurisdiction which arise from prenatal and pre-implantation diagnosis and the treatment of embryos on the basis of their findings.

The Commission notes that prenatal diagnosis is implemented in our country since the 1970's and is relevant to a large number of expectant parents while pre-implantation diagnosis began to be provided in the context of assisted conception during the present decade and the number of people affected is rising.

These relatively new possibilities offered by the technology of reproduction, however, are associated with a major ethical dilemma of embryo treatment. Indeed, through these tests expectant parents can find out whether the embryo is affected by developmental abnormalities or serious diseases. At all events, this knowledge prepares them in time for whatever may come. But in case some abnormality or disease is identified in the embryo and considering the very small number of currently available intrauterine therapies, future parents are confronted with two choices: either to accept the continuation of the reproductive process in the near certainty that they are going to have a child with serious health problems or to interrupt the pregnancy (or refrain from embryo implantation in the case of *in vitro* fertilisation).

It would be highly desirable that these were not the only available options; that effective cures were available to treat any potential problem. But since this is not so, it is important to consider the aspects of this dilemma from the ethical viewpoint in order to specify the responsibility of everyone concerned (parents, physicians, the State) and develop relevant guidelines.

1. *Problem description*

A. *Technical possibilities*

1. *Prenatal Diagnosis*

“Prenatal diagnosis” (PD) signifies the testing of the embryo *in vivo* with certain methods in order to identify in time potential abnormalities or diseases. These methods are non-invasive (e.g. ultrasonography, maternal blood tests) or invasive (amniocentesis, trophoblast testing). In the case of invasive methods embryo cells are harvested by puncture from the amniotic fluid or from the trophoblast. Invasive prenatal tests detect severe chromosomal abnormalities (e.g. Down Syndrome) and genetic conditions (e.g. thalassemia, cystic fibrosis) and also non-pathological phenotypic characteristics (e.g. the embryo’s sex). They are usually conducted during the first trimester of pregnancy.

2. *Pre-implantation diagnosis*

“Pre-implantation genetic diagnosis” (PGD) means testing *in vitro* embryos that were created in the context of assisted conception. This test can identify severe abnormalities and diseases as well as the embryo’s gender. It is performed on 1-2 blastomeres that are removed from the embryo without destroying it. Pre-implantation diagnosis is not yet applied universally in assisted conception, as it requires specialized laboratory equipment and a matching level of expertise.

B. *Ethical concerns*

As mentioned in the introduction both prenatal and pre-implantation diagnosis informs us of the state of the embryo’s organism and provides some scope for “choice”. In this sense, we are in a position to control the procedure of reproduction by “preventing” the birth of children with severe abnormalities or diseases or, perhaps, of “undesirable children” in general.

The first issue that must be addressed here is whether we should make such choices in the first place. A subsequent question, in the case of affirmative answer to the first question, is which choices are ethically justified. In addition to these fundamental questions we will also consider related socio-political issues.

II. Directions

A. The fundamental ethical issues

1. Choice of embryo as a general possibility

The Commission holds that, in principle, parents are entitled to the right of choice of embryo following a prenatal or pre-implantation diagnosis in general. Exploiting the means availed by modern technology to prevent pain, suffering, or even the exposure of someone to social prejudice is an obligation emanating from respect for human dignity. To accept to give birth to children with severe health impairments, justified as it might seem in absolutely exceptional situations (e.g. when the people involved have serious fertility problems), is ethically questionable. Indeed, even if such acceptance emanated from the particular metaphysical convictions (and not the mere selfishness) of the parents-to-be, it cannot be overlooked that it betrays inadmissible disregard for a person's future quality of life.

It must be strongly emphasized that such prevention does not mean to deny in any way the unequivocal condemnation of any and all unfavourable social discrimination against our fellow human beings who happen to be born and live with serious health problems. According to the Commission, it is a vital duty of society and the State to ensure a life of dignity specifically for these people in an environment of freedom and equality.

2. Terms of choice

Choice, in view of the above, is part of the fundamental right of future parents to reproduction and family: in this case, to the responsibility of choice lies with the parents alone.

But if this choice is to be acceptable, certain conditions must be met. These are:

- To safeguard the *freedom* of the final decision by the provision of appropriate prior information by the physician on the findings of prenatal or pre-implantation diagnosis as well as their impact on the health of the expected child.
- To guarantee the ethical *purpose* of the final decision by ensuring that prenatal or pre-implantation tests are performed solely for the purpose of serious health considerations according to the following.

3. *Acceptable considerations of health*

The Commission believes that only serious health considerations concerning the health of the child itself or of another person must be investigated. *The investigation must be restricted to data that have been proven to correspond to a pathological phenotype.*

In the Greek context, with regards to the first case, such considerations refer to chromosomal abnormalities (trisomies) and, in the case of genetic diseases, to thalassaemia. Physicians *should be obliged to* recommend the diagnosis of these conditions (independently of whether expectant parents will follow their advice or not).

Other diseases either single gene (e.g. cystic fibrosis) or multifactorial (e.g. various types of cancer) should be tested following the physician's recommendation on the condition that there is relevant family history. In the Commission's opinion, genetic diseases that develop in adult life or at an advanced age (Huntington's chorea, Alzheimer's disease) should not be tested for (*also in view of the right to ignorance*).

It must be stressed here that the choice of embryo is not always justified, especially in those few cases where an effective treatment is currently available, before or after birth. In the context of the prior information to be provided by the physician, these possibilities – if available – should be clearly communicated to the parents.

4. *Choice for the purpose of saving another*

In the Commission's view the choice of an embryo found to be compatible with a diseased person in order to obtain biological material to save the life of the latter is morally justified provided the health of the embryo is not harmed. The fact that, by being born, a person has contributed to saving a human life, far from reducing them to

mere “instruments”, reinforces their self-respect and the love they receive from their kin throughout their future lives.

5. *Choice of gender*

The choice of the embryo’s gender is similarly justified only for serious health considerations, namely for the prevention of sex-linked diseases. The Commission does not see any justification in the choice of gender for “social” reasons (e.g. to “balance” the gender of children within the family). Despite the validity of some arguments, the social prejudice which continues to prevail with regard to gender, even in European societies, would lead to undesirable effects should the choice of gender be granted.

B. Related issues

1. Professional recognition of geneticists – Supervision of laboratories

The importance of prenatal and pre-implantation diagnosis in contemporary perceptions of reproduction calls upon the Authorities to ensure appropriate conditions for their application. In this respect, the Commission believes that parents should be supported with informed counselling and that genetic testing should be entrusted to certified geneticists. To this purpose, it is necessary to create a formal distinct professional specialization. Professional geneticists should receive additional interdisciplinary training (medicine, psychology, sociology, bioethics, etc.) and be licensed based on these qualifications by the State, be they employed in public or in private laboratories.

For the same reason, the Authorities must create a system of supervision of genetic laboratories. Laboratories should guarantee a high quality of service given the sensitive nature of reproductive issues and must, therefore, be controlled both *ex ante* (through a licensing system) as well as *ex-post* (through inspections) by public authorities.

2. *Financial considerations*

The cost of invasive prenatal and, in particular, pre-implantation diagnosis is very high and, for the most part, is currently borne by expectant parents.

Given the importance of these tests to fully exercise the right to reproduction and family, the Commission believes that the cost of testing for the most frequent chromosomal abnormalities and genetic diseases in the Greek context should be fully reimbursed by social security. The same must apply for diseases whose likely manifestation in a particular person is documented by scientifically sound indications (based on their medical history).

In contrast, the cost of testing for more rare conditions should continue to be borne entirely by the parties concerned.

Dissenting Opinion

D. Roupakias

Mr. Roupakias holds that the rejection (by killing) of a human embryo is part of the policy of crypto-eugenics leading slowly but steadily to the implementation of a hidden agenda of practical choice and genetic improvement of human beings through the rejection of genetically undesirable embryos at the beginning of their lives. No doubt, left at the hands of an anonymous “improver”, prenatal and, especially, pre-implantation testing represent an excellent method of negative, to say the least, choice and genetic improvement. The genetic selection of humans, also known as eugenics, yet so starkly condemned in the minds of post-war generations, will be presented by our modern secular civilization, and more so in the century we are traversing, as a legitimate option through the rejection of embryos making it look as a therapeutic choice. The answer to the fundamental bioethical question of acceptance or non-interruption of the life of an embryo is directly dependent on answering the following question: What is a human being? At this point, two diametrically opposed views can be expressed. According to the first one, with which I agree, human beings have a Divine origin and are characterized by psychosomatic inherence, the moment of conception representing the common beginning of body and soul in time. Seen in this light, the interruption of pregnancy or the elimination of an embryo amounts to a violent separation of body and soul and, thus, murder. According to the second view,

human beings are the product of genes as raw material and of the impact of the environment, not of God.

One's response to the above bioethical question depends on the view one takes. People who endorse the first view usually reject the possibility of choice or killing the embryo whereas people who hold the second view accept it with relative ease.

Given this diversity of opinion, the State may decide to legislate on the issue taking into account the following:

1. Generally, the genetic improvement of human beings *via* choice at all stages of development of the human body is not acceptable, and,
2. In respect to negative choice as regards those situations that able-bodied individuals of our society still view as tragedies, the heavy moral charge of the basic dilemma of "choice" cannot lead to single-minded value judgements. This means that the dilemma should be answered by each person according to their personal beliefs about what constitutes a human being in the context of their personal autonomy and responsibility.

Translation: Ch. Xanthopoulou