

# **“The Risks and Ethical Problems of Applying Genetic Testing in Underdeveloped Countries”**

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## **Summary**

Potential risks of biotechnological applications, especially in the medicine arena, have been discussed in the medical ethics and other research areas by the developments in biotechnology. The effects of this technology upon the underdeveloped countries have entirely different results in terms of the education levels, socio-economic status, gender and religiousness when compared to the developed ones which lead to biotechnological developments. Thus, these results can be summarized under the subtitles of attitudes towards biotechnology and abortions, sex selections, health insurances and impossibility of accessing this technology.

In this paper, these issues will be argued through the survey results of Turkish people and literature surveys of other underdeveloped countries.

**Key words:** *Abortion, Biotechnology, Genetic testing, Sex selection, ‘New maternity’ and ‘new paternity’ concepts, Underdeveloped countries*

## **I. Introduction**

Almost all technological developments have been in parallel to many social problems. But in many of them, these problems occur simultaneously or shortly after its use. Biotechnological applications in agriculture, animal husbandry or industry fields have some indefinite social implications which occur in again an indefinite time. However, when these

applications are applied in health –medicine- and reproduction practices, the social outputs of these would be handed earlier than those of the other fields.

Developments in modern biotechnology are regarded as including many social problems especially for underdeveloped and developing countries. These problems related to many subjects include economic, social, legal and ethical dimensions. In this article, the risks and ethical problems of applying genetic tests, which can be regarded as the initial and broad uses of modern biotechnology in health in underdeveloped world, will be submitted by means of the statistical data gained from Ankara, Turkey. In brief, it is claimed in this study that, the broad and uncontrolled uses of genetic tests will lead to broad problematic social results.

## **II. Methods**

It is known that a social scientist cannot prepare a meaningful study if it doesn't include statistical data or has a theoretical dimension. Hence, both quantitative and qualitative survey results are considered in this study.

The quantitative and qualitative survey results are gained from the study of Evsel (2007), who interviewed with 120 people from two different districts which reflect different socio-economic statuses of Ankara, Turkey, about their opinions related to genetic testing. On the other hand, other underdeveloped and developing country data is brought together from literature survey.

## **III. Findings and discussion**

In the underdeveloped countries, people have encountered the most serious problems in their health care. These problems are generally connected to uncontrolled birth rates in those countries. A writer gives statistics to support this claim: 'for every child in a developed country in 1990, there were 7 children in the developing countries' (Kaushik 1994, 92). As Arocena & Senker (2003, 16) writes, one of the principal findings of the UNDP research on human development is that poverty is mostly widespread in more unequal societies, and as we see in Latin America, inequality can represent a major obstacle to development. Actually, it is widely known that accessing to technology and modern medicine is the main problem in underdeveloped world. Anyhow, it is not a coincidental explanation that 'technology is created in response to market pressures – not the needs of poor people who have little purchasing power (quoted from Arocena & Senker 2003, 17; UNDP 2001, 3). This inequality

in accessing medical facilities can be seen in many developing countries. According to Bhardwaj & Macer (2003, 53-54):

...although average world per capita income grew at an average of 2.4 percent per annum, about a billion people still lack the resources to meet their most elementary needs, and around 80% of population of the world population lives in developing countries where people don't even have access to basic medical facilities and health care.

The periodic medical controls are closely related to the socio-economic structure. It is seen in the table below that Turkish people go to the doctor when it is needed, in general. The people who live in Kavaklıdere, which has a relatively high socio-economic structure, have the access to relatively better health care opportunities and institutions.

**Table I.** The Frequency of going to a doctor and the places where are gone for health care

|                               | District    |      |       |      | TOTAL |      |
|-------------------------------|-------------|------|-------|------|-------|------|
|                               | Kavaklıdere |      | Mamak |      | N     | %    |
|                               | N           | %    | N     | %    |       |      |
| State hospital per month      | -           | -    | 2     | 3,3  | 2     | 1,7  |
| State hospital once Six Month | 3           | 5    | 4     | 6,7  | 7     | 5,8  |
| Private clinic once six month | 13          | 21,7 | 2     | 3,3  | 15    | 12,5 |
| State hospital once a year    | 1           | 1,7  | -     | -    | 1     | 0,8  |
| Private clinic once a year    | 3           | 5    | 1     | 1,7  | 4     | 3,3  |
| State hospital when needed    | 17          | 28,3 | 37    | 61,7 | 54    | 45   |
| Private clinic when needed    | 22          | 36,7 | 5     | 8,3  | 27    | 22,5 |
| Do not go in general          | 1           | 1,7  | 9     | 15   | 10    | 8,3  |
| <b>TOPLAM</b>                 | 60          | 100  | 60    | 100  | 120   | 100  |

Chi square = 36,721

P < .000

### III. a. Some underdeveloped solutions and cures / rejection of modern medicine

Traditional and modern applications / behavioral habits collide with each other in medical arena as they do in all others. According to Bhardwaj and Macer (2003, 52), in some African countries up to 80%, and in India 65% of the population depends on traditional medicine to help meet their health care needs. Opposed to the modern medicine, traditional medicine covers some attempts for the treatment of some desperate illnesses; to illustrate, in

South Africa, men rape young children because of a belief that sleeping with a virgin will cure them of AIDS; or, in India people with HIV have been killed by some communities, despite the high prevalence of HIV (Bhardwaj & Macer 2003, 52). Many inconceivable methods are used in underdeveloped countries especially when people are able to find no way out; in other words when modern medicine does not offer a better solution.

Another underdeveloped –so-called- solution of underdeveloped world is the misuse of new technologies. A man can easily realize that people of underdeveloped world use technology not to have a rational and healthy life, on the contrary, to make their traditional rituals easy to apply.

### **III. b. Underdeveloped countries and abortion: not a ‘new maternity’ but a ‘new paternity’ concept for underdeveloped world**

Beliefs, religions and other social values are some of the reasons for the rejections of modern medicine in underdeveloped world. However, modern medicine does not offer any method aside from abortion for the parents who have a baby with a fatal genetic disorder. This issue, abortion, includes many ethical problems, especially for sex selection. It is known that underdeveloped countries were against abortion because of their traditional and religious values in general. Moreover, they can use this technology in accordance with these values by aborting undesirable baby rather than the baby with genetic disorders.

This misuse is in use through amniocentesis and some other genetic testing. According to Bhardwaj & Macer (2003, 53) in India, there are well documented abuses of amniocentesis for sex selection. A few respondents made comments that it should not be used for sex selection, but otherwise the issue was not addressed here. Some would argue sex selective abortions are comparatively better than female infanticide, but it is a controversial issue (Bhardwaj & Macer 2003, 53). Bhardwaj & Macer (2003, 53) summarize this issue as ‘the access to commercial services such as amniocentesis for sex selection, reproductive technology, and to drugs and hormones made by modern biotechnology like human growth hormone, in a developing country means it is very difficult to limit the use and misuse of these technologies by some members of the community’.

In order to make some comparisons with the other underdeveloped and developing countries, Evsel (2007) asked her male and female participants whether they or their wife wanted to accept abortion when they have learnt the existence of a serious fatal defect in their ten months old baby through genetic testing. Ten month is a critical time period in

Turkish people's pregnancy thoughts. One of these reasons takes its source from legislative authorities of Turkey. According to the 5<sup>th</sup> theme of the 2827 numbered Act of parliament for population planning in Turkey (27 Mayıs 1983);

“It is possible to make arbitrary abortion of fetus until the 10 weeks of pregnancy only if there will be no probability of health problem for the mother. If the pregnancy duration is higher than 10 weeks, that termination may occur only if that pregnancy gives or will give harm to the mother's life or if the unborn child will cause defected generations after itself and only with a well-grounded report which is written by an obstetrician and a specialist from a related branch”.

In addition to this information, Evsel (2007) reminded her participants that most of the defects and handicaps which get along well with the life can be obtained through USG, amniocentesis, and other advances of medical techniques only after 10 weeks of pregnancy. She found that 40, 7 % of the total participants think they do not accept or they are indecisive about the abortion in this situation. 17 % of the participants expressed their opinion as “I would not accept it because of my religious belief”. One of these participants answered this question with diction: “even if it was a lump of mud, you would take it”. In other words, even when your child is a mess, you will accept and endure it according to a Turkish proverb! This answer is important because it represents a sort of traditional view.

**Table II.** *Distribution of attitudes according to the districts towards the abortion if there is a fatal disorder in pregnancy*

|              |                    |          |              |          |              |          |
|--------------|--------------------|----------|--------------|----------|--------------|----------|
| <b>TOTAL</b> | 57                 | 100      | 56           | 100      | 113          | 100      |
|              | <b>District</b>    |          |              |          | <b>TOTAL</b> |          |
|              | <b>Kavaklıdere</b> |          | <b>Mamak</b> |          |              |          |
|              | <b>S</b>           | <b>%</b> | <b>S</b>     | <b>%</b> | <b>S</b>     | <b>%</b> |
| Yes          | 47                 | 82,5     | 37           | 66,1     | 84           | 74,3     |
| No           | 3                  | 5,3      | 12           | 21,4     | 15           | 13,3     |
| No comment   | 7                  | 12,3     | 7            | 12,5     | 14           | 12,4     |

Chi square = 6,582

P < .05

Bhardwaj & Macer give some statistics about the attitudes of the people from the underdeveloped countries: in a 1993 survey 41% of Indian people strongly disagreed to abort a 4 month-old fetus if it was not suffering from any diseases; this is certainly the highest rate among the ten countries in Asia and Oceania that were surveyed. This shows the sanctity of life is a major ethical issue for Indian people. Nevertheless, 38% agreed to abort if the fetus was suffering from some congenital malformations, showing some pragmatism. Therefore, this survey and other ones have showed that there were not major religious differences among Hindus, Christians and Muslims in India when it comes to decisions over prenatal diagnosis (Bhardwaj & Macer 2003, 53).

**Table III.** *Distribution of attitudes according to the districts towards the abortion if the serious disorder is learnt in the fourth month of the pregnancy*

|              | District    |      |       |      | TOTAL |      |
|--------------|-------------|------|-------|------|-------|------|
|              | Kavaklıdere |      | Mamak |      |       |      |
|              | S           | %    | S     | %    | S     | %    |
| Yes          | 39          | 68,4 | 28    | 50   | 67    | 59,3 |
| No           | 6           | 10,5 | 20    | 35,7 | 26    | 23   |
| No comment   | 12          | 21,1 | 8     | 14,3 | 20    | 17,7 |
| <b>TOTAL</b> | 57          | 100  | 56    | 100  | 113   | 100  |

Chi square = 10,136

P < .01

Evsel (2007) found that the rates of people who agreed with abortion in the event of a genetic disorder in initial pregnancy, degraded in the event of 10 weeks pregnancy (from 74,3% to 59,3%). There is a similarity with the rate of Indian people if we accept 'no comments' as 'disagree' (suppositional rate: 40,7%). It is seen in Table 3 that people from socio-economically lower district (Mamak) disagree with abortion in this case. Their opinions may be related to their cultural or religious beliefs in general.

According to Qiu (1993, 115), 'the medicine in developing countries has been paternalistic'. In his article, he likens a person of a developing country to a water drop in the sea; thus, that person identifies him/herself as a member of his/her family or clan or

community. As a result of this, 'it is very difficult to get individual informed consent from them without family or community support; the consent has to be obtained with family and community aid' (Qiu 1993, 116). Bhardwaj & Macer also give a big importance to informed consent ; they accept it as quite important for the ethical issues of practice of medical applications in developing countries. They exemplify this by referring to India; according to them (2003, 53), in India the courts have recognized the concept of informed consent and it would be an accepted norm; however, exercise of consent and choice is limited by the situation of poverty as in all developing countries (Bhardwaj & Macer 2003, 53).

In Evsel (2007)'s study, one of the participants' answer was remarkable in point of informed consent. The participant was male and questioned as 'would you (if the participant is female) want / your wife (if the participant is male) to undergo an abortion if the prenatal tests show a serious disorder in your baby's genes'? He said that he married a short time ago and his family wanted a grandchild a lot. If this assumed baby who had disordered genes were male, probably his family would not want their bride to undergo an abortion. Even if she gave a decision for the abortion they could prevent her from this surgery because this baby, who would maintain their surnames, would be the first and male grandchild of the large family. This case is crucial in order to show the important role of groom's family in the bride's decisions about her pregnancy. The informed consent of bride can not be the point of issue in her pregnancy even if she is pregnant for a baby with genetic diseases. Hence, we can not talk about a 'new maternity' for underdeveloped and developing countries, we can only talk about a 'new paternity' for these societies.

This situation is important because even if the pregnant woman signs her document which accepts or refuses the abortion, that may not represent her own decision. The same inducement is valid for the pre-implantation genetic diagnosis, which is another so-called solution of modern medicine for births with genetic disorders. This new method of modern biotechnology offers healthy babies whose fetuses are arranged from healthier ovum and sperms and constituted in vitro fertilization. The socio-economic environment of the prospective mother and of especially her husband's family is effective in this serious decision. This relatively new method of biotechnology can be regarded as another and minimal arguable way of sex selection.

Anyhow, it is obvious that people who carry serious genetic disorders in their genes, and thus, are placed in the most risky group have no opportunity to take the advantage of this new technology because they are poor and living in an underdeveloped country and there is

no or rare access for these reproduction methods. Others, relatively lucky people who have the opportunity to use these technologies, constitute the target group of modern reproductive technologies; hence, they are more responsible for the misuse of the technology as well.

#### **IV. Conclusion**

Our grand mothers and fathers had lived with some disorders in their genes. People all over the world, and also I, have many disorders in their/my genes. However, these disorders do not constitute any obstacle to maintain our lives. Hence, it is very important to have a healthy communication with patients / pregnant women even if they are in a serious problematic situation. Genetic testing helps doctors and biologists in giving the best decision for their clients but this does not mean that the client or her family have no right on the situation. On the contrary, it is impossible to provide an environment to the client to give her decision without any intervention of her partner/his family or the specialist in especially underdeveloped/developing country where it is very difficult to decide by itself.

There can be a rejection to the applications of modern medicine and biotechnology because of some traditional beliefs. However, it gains importance to understand if that application will be indispensable for underdeveloped world and to talk and write the advantages of it.

Even if the people of the countries that we consider have a willing to use the technology, there is a huge problem, that is: the inability to access it!

An important social problem of underdeveloped countries and small residences is endogamy. However, modern biotechnology tries to solve these kinds of social problems with asocial, biological or surgical techniques. Thus, from now on, we can imagine a society with a lot of totally healthy endogamy babies and individuals. Nowadays, people have started to reach this result with amniocentesis and abortions; moreover, in the light of this development, we can make a prediction about the possibility of using pre-implantation technologies to realize this aim in the immediate future.

Another social problem of underdeveloped countries like Turkey is ‘fellow wife’ concept which means polygamy. Many people, even medical specialists, claim that biotechnology gives people hopes about selecting desired sex with pre-implantation genetic diagnosis; so the ‘fellow wife’ problem will be worked out. This is completely fictitious because like many other social problems, this problem does not have only one cause. A man get married to another woman to have male children to survive his surname and not to divide

his wealth, it is true. However, having more wife and children proves his wealth and status in his social environment. Thus, you can give him opportunity only to choose those children from the only male babies by pre-implantation genetic diagnosis. Needless to say, that will produce not a solution but new other social problems.

Many people live in rural and suburban areas of the countries and have less chance to have an access to these tests and technologies. It is seen in this study that when people have the access for getting the testing, they used /or imagined to use them so as to have their intended babies. Can we think of optimism about this inequality in accessing biotechnology? It would not be sufficient. There must be a consensus in the specialists about enrolling testing results; the people who are in the genetically risky group must be determined and benefited from the advantages of this technology; authorities must prevent people from using this technology unnecessarily and people must be trained about avoiding the abuse of these technologies in an arbitrary way, such as aesthetics surgeries. People must not forget the Nazi history and they must keep in their mind of the possibility of ‘a new eugenics danger’ which can be achieved by modern biotechnology.

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