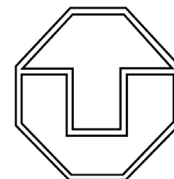


# Genetic counselling and diagnostics: opinions of counselees, professionals, and members of lay organizations

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## Introduction

Genetic diagnostics are more and more becoming a common tool for the detection of genetically caused diseases. However, it is a special diagnostic that also provide risk estimations for other family members. The Commission of Public Awareness and Ethical Problems of the German Association for Human Genetics (GFH) demands that (i) genetic diagnostics should only be offered by geneticists, (ii) that any decision to undertake genetic analysis should be the result of informed consent, and (iii) that healthy children should not be diagnosed. In Germany, pre-implantation genetic diagnostic (PGD) is not allowed by law. However, the opinions of professionals and families affected by genetic diseases show disagreements with this law.

## Methods

The results are part of a large study (first section starting in August 2002 and ending at the end of 2003) to investigate the influence of genetic counselling on ethical values, living habits and educational issues (second and third sections after counselling and 6 months later, respectively). Here, the basic results (first section) obtained by questionnaires before counselling are presented. The answers were compared among the opinions of groups of professionals and members of lay organizations. The questionnaire contained ten questions relevant to ethical issues with the choice of three possible opinions (not allowed, allowed in special circumstances, allowed in general). The opinions of 13 groups (n = 1.017) (12 control groups + the group of counselees) regarding to the 10 issues will be presented:

- Group 1:** medical students, 4th semester 2000 (n = 20)
- Group 2:** medical students, 5th semester 2003 (n = 79)
- Group 3:** medical students, 5th semester 2002/03 (n = 188)
- Group 4:** medical students, 7th semester 2002/03 (n = 24)
- Group 5:** medical students, 7th semester 2003/04 (n = 153)
- Group 6:** students of the Technical University other than the Medical faculty 2002/03 (n = 14)
- Group 7:** students of midwifery 2003 (n = 31)
- Group 8:** physicians in training for industrial medicine 2003 (n = 70)
- Group 9:** members of families of hereditary cancer diseases 2003 (n = 38)
- Group 10:** active members of the German lay organisation for Huntington's disease 2002/03 [(DHH) n = 76]
- Group 11:** active members of the German lay organisation for heredo ataxias 2002/03 [(DHAG) n = 67]
- Group 12:** accompanying persons at our genetic counselling unit 2002/03 (n = 15)
- Group 13:** counselees of our genetic counselling unit 2002/03 (n = 242)

The following questions/request for opinions were contained in the questionnaire:

### A) Genetic diagnostics ...

- (1) ... should never performed.
- (2) ... should only performed in the framework of genetic counselling after the provision of extensive information.
- (3) ... should be carried out by every physician in the framework of routine diagnostics.

### B) Every genetic counsellor who finds an additional genetic risk following pedigree analysis ...

- (1) ... should never divulge this risk to the counsellee.
- (2) ... should divulge this risk only if it is requested by the counsellee.
- (3) ... should divulge this risk irrespective of whether it is requested.

### C) Every genetic counsellor who finds a genetic risk following pedigree analysis in the family ...

- (1) ... should divulge this risk only if it is requested by the family members.
- (2) ... should divulge this risk to family members if the counsellee wishes it.
- (3) ... should divulge this risk to family members irrespective of whether it is requested.

### D) The genetic diagnosis of a healthy child ...

- (1) ... should be never carried out.
- (2) ... should be carried out in cases when the disease is preventable.
- (3) ... should be performed if the parents request it.

### E) Every healthy person ...

- (1) ... has to decide for himself whether to undertake predictive diagnosis.
- (2) ... visiting a practising profession with special responsibility is duty-bound to undertake predictive diagnosis.
- (3) ... is duty-bound to undertake predictive diagnosis in order to reveal genetic disorders before symptoms appear.

### F) Results of genetic analysis ...

- (1) ... should never be announced to employers and insurance companies.
- (2) ... should be announced to employers and insurance companies in agreement with the individual.
- (3) ... should be generally available to employers and insurance companies.

### G) The manipulation of genes ...

- (1) ... should be forbidden in general.
- (2) ... should only be carried out to prevent or cure genetic diseases.
- (3) ... should be carried out if the parents wish to have a designed baby.

### H) Pre-implantation genetic diagnostic (PGD) ...

- (1) ... should never carried out.
- (2) ... should only be performed if there is a high risk of a genetic disease.
- (3) ... should be undertaken for every couple who request it.

### I) Prenatal diagnosis (PND) ...

- (1) ... should be forbidden in general.
- (2) ... should only be carried out if there is a high risk of having a handicapped child.
- (3) ... should be offered to all pregnant women to prevent the birth of a handicapped child.

### J) Termination of pregnancy after the 3<sup>rd</sup> month of pregnancy ...

- (1) ... is not to justified in general.
- (2) ... is justified in cases where the physical and/or psychological health of the mother will be affected (so called "medical indication").
- (3) ... is justified in cases where it is known that the child will suffer from a genetic disease (so called "embryopathic indication").

## Discussion

The opinions of persons of all groups agree very well in most cases. However, there are some striking differences. The opinions of the participants and the GFH differ with regard to the testing of a healthy children (fig. D). About 80% of active members of the Huntington's association agree that results of genetic analysis should never be offered to employers and insurance companies (fig. F). This may be the result of extensive discussions of these issues within the lay organization. Only students of midwifery (about three quarters) think manipulation of genes should be forbidden (fig. G). In the other groups, the thinking seems to be that manipulation should be allowed to prevent diseases. There is a very high acceptance of PID (between 20% in the group of students of midwifery to two thirds in the group of the association for heredo-ataxias) (fig. H). The atactic persons questioned perceive their daily loss of function and want to prevent this happening to their children and grandchildren. We have been able to show that the opinions of medical students regarding PND change during their training: PND not only should be offered to every pregnant women but also if there is an increased probability of having a handicapped child (fig. I). There are clear differences between professionals and non-professionals within regard to termination of a pregnancy (fig. J): for the first group, it is only justified if there is a medical indication, whereas for the latter it is also justified if the baby is going to be handicapped. This disagrees with the actual law in Germany.

## Conclusion

Ethical values in connection with genetic counselling and diagnosis are not the same between some groups of students, members of affected families, members of lay organizations or physicians and, especially in the case of PGD, do not agree with the opinion of the German government. However, these discussions must continue, unique guidelines must be established when necessary and the current German law should be adjusted.

## Results

See the following graphs.

