Adolescents’ opinions about genetic risk information, prenatal diagnosis, and pregnancy termination

Marleen Decruyenaere, Gerry Evers-Kiebooms, Myriam Welkenhuysen, Jacqueline Bande-Knops, Veerle Van Gerven, Herman Van den Bergh

Abstract
Advances in genetics create increasing possibilities of diagnosing and preventing genetic disease. In most countries, the community is poorly informed about the role of genetic factors in human disease and about genetic testing and its social, emotional, and ethical implications. School education about genetics may improve this situation. Students are, of course, the adults of the future and the potential users of the new genetic tests. To gain further insight into the perception of genetic risk of adolescents and their perception of the new genetic techniques and as a starting point for setting up an adequate information campaign in Flanders, we assessed the opinions and beliefs of students with regard to health, genetic diseases, genetic risk, and genetic testing.

A standardised interview and questionnaire were administered within the scope of the yearly medical check up of 166 fifth grade students. They were randomly selected from the group of all fifth grade high school students in seven different schools.

This paper focuses on the attitudes of adolescents towards obtaining genetic information, towards prenatal diagnosis and pregnancy termination. Adolescents in Flanders are interested in being informed about genetic risks and genetic diseases and in making use of prenatal diagnosis because they want to make informed reproductive decisions in the future and to be emotionally prepared for the birth of an affected child. They adopt a critical attitude towards pregnancy termination. The association between these attitudes and several relevant factors was investigated. This showed significant correlations between some attitudes and general health related prevention, perceived burden of genetic diseases, the importance of the value “own health”, the perceived role of society, and the regularity of religious practice. Some points for special attention were formulated with regard to information campaigns for adolescents.


In the past decades, there has been increasing awareness of the importance of genetic factors in the causation of human diseases. Many genetic diseases impose serious burden and suffering, not only on the affected person but also on the parents and other family members. Advances in genetics have created promising possibilities for the diagnosis and prevention of genetic disease. In most countries, however, the community is poorly informed about basic genetics, about the role of genetic factors in human disease, and about genetic testing. As a consequence, only a minority of the potential clients find their way to a genetic centre. Another consequence is that counsellees have difficulties in understanding the information given during genetic counselling and this may impede free, fully informed decision making.

The genetic centres and the government should therefore do whatever possible to provide information to the public. Professionals as well as patient organisations agree that school education on genetics should get special attention.14 Students are the adults of the future and the potential users of the new genetic tests; thus they should be informed about genetic risks, genetic diseases, and genetic tests and about the existence of genetic centres. To ensure that the information given during genetic counselling is fully understood, education about basic genetic facts and principles should be provided. The students should furthermore be sensitive to the values and norms which play a role in decision making about genetic problems.

It is important to gain more insight into their spontaneous beliefs and opinions before setting up an educational or information campaign about genetics for adolescents. Are young people interested in genetic information and genetic risks? Are they prepared to receive information about a subject which is not relevant for them at their age, namely reproductive decisions and genetic counselling? Do they realise that there are psychological and ethical implications of modern genetic technology? This paper focuses on the attitudes of high school students towards obtaining information about personal genetic risks, towards prenatal diagnosis, and pregnancy termination. We also examine the association of these attitudes with variables such as the attitude towards prevention in general, some basic knowledge of genetics, perceived severity of the disease, perceived self-concept of a child with a severe genetic disease or congenital malformation, perceived susceptibility to having such a baby, the perception of society’s role regarding pre-
vention of genetic disease, the importance of values, and sociodemographic variables (sex, education, the occurrence of genetic diseases in their family and in their environment, religious practice).

**Subjects and methods**

**SUBJECTS**
The subjects comprised 166 fifth grade high school students. About 53% were following a general education and the others a technical education; 45% were male and 55% female. The mean age was 16-74 years (range 16–20 years).

**PROCEDURE**
The study was performed in cooperation with the Medical School Health Service. The sample was selected at random out of the list of names of all fifth grade students from seven different schools. In Flanders, every fifth grade student has to undergo a medical check up at the Medical School Health Service. The selected students were invited to participate in a research project while waiting for their turn to be examined. No one refused to take part. A questionnaire was administered during a standardised interview (period January to May 1993).

**QUESTIONNAIRE AND INTERVIEW**
The questionnaire and standardised face to face interviews were aimed at evaluating knowledge and opinion about health problems, genetic disease, perceived susceptibility to genetic disease, and expectations with regard to genetic testing. The present paper only describes and analyses the attitudes towards genetic information, prenatal diagnosis, and pregnancy termination. These attitudes were measured by multiple choice questions assessing the personal intentions of the students with respect to some hypothetical actions, namely (1) seeking information about genetic risks before reproductive planning, (2) undergoing prenatal diagnosis to detect serious disease or malformations in the fetus, and (3) undergoing a pregnancy termination should the fetus have (A) a serious mental handicap, (B) a serious physical handicap, or (C) a serious genetic disease (see Results section for more details). During the interview, the students could give arguments for their answers, as well as spontaneous comments.

The following variables were considered to be potentially related to these attitudes.

**General preventive attitude**
This was measured by the European Health and Behaviour Survey (EHBS; 25 items), which assesses the importance of a range of different activities for health maintenance, such as cigarette smoking, alcohol consumption, breast self-examination, testicle self-examination, and participation in screening and vaccination programmes. The students responded on a 10 point scale (1 = low importance to health, 10 = great importance to health).

**Basic awareness of genetics**
This was measured by 10 simple multiple choice items about basic genetic terms and facts (chromosome, gene, recessive, dominant, consanguinity . . .).

**Perceived severity of a handicap or a genetic disease for the parents**
The students had to evaluate the perceived burden for the parents of the birth of a child with (A) a serious mental handicap, (B) a serious physical handicap, and (C) a serious genetic disease on a seven point scale (1 = not serious, 7 = very serious).

**Perceived self-concept of a child with a handicap or genetic disease**
The subject had to rate how they thought a child feels when it has (A) a serious mental handicap, (B) a serious physical handicap, and (C) a serious genetic disease. The Health Orientation Scale (HOS), based on the semantic differential technique of Osgood, was used. It consists of 12 bipolar five point Likert scales: good-bad, afraid-unafraid, guilty-not guilty, ashamed-unashamed, weak-strong, shocked-relieved, sad-happy, marked-unmarked, able-able, angry-pleased, inactive-active, sick-healthy. We calculated a mean score per subject over the 12 items. A higher mean score reflects more positive feelings.

**Perceived susceptibility**
This was measured by two multiple choice items: (1) an estimation of the risk of a random couple in the population of having a newborn child with a genetic disease or congenital malformation, and (2) an estimation of their own chance of having such a baby. The students could choose one out of seven risk intervals: less than 1%, 1–2%, 3–5%, 6–10%, 11–20%, 25%, and 50%.

**Perception of the role of society in preventing genetic diseases**
The students had to indicate whether they agreed with the following two statements. (1) Society has to try to prevent the birth of seriously handicapped children by providing information about genetics to the general population. (2) Society has to try to prevent the birth of seriously handicapped children by stimulating young couples to ask a medical doctor for information about increased genetic risks before having children.

**Values**
The subjects had to rate the importance of seven values on a seven point scale (1 = unimportant, 7 = very important). We selected
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Table 1 Personal intentions with regard to three hypothetical future actions (multiple choice questions)

<table>
<thead>
<tr>
<th>Would you ask a doctor for information about increased genetic risks before your first pregnancy?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certainly not</td>
</tr>
<tr>
<td>Probably not</td>
</tr>
<tr>
<td>I don’t know</td>
</tr>
<tr>
<td>Probably</td>
</tr>
<tr>
<td>Certainly</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Would you use prenatal diagnosis when pregnant to detect serious diseases in the child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certainly not</td>
</tr>
<tr>
<td>Probably not</td>
</tr>
<tr>
<td>I don’t know</td>
</tr>
<tr>
<td>Probably</td>
</tr>
<tr>
<td>Certainly</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Suppose that in the future you and your partner are in one of the following situations. Would you decide to terminate the pregnancy?</th>
</tr>
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<tbody>
<tr>
<td>(A) A pregnancy with a child that is seriously mentally handicapped</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>I don’t know</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>(B) A pregnancy with a child that is mentally normal, but who has a serious physical handicap</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>I don’t know</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>(C) A pregnancy of a child with a serious genetic disease</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>I don’t know</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

“having success in life”, “pleasure and relaxation”, “safety in family life”, and “social appraisal” from the hierarchy of Rokeach and added “health”, “bearing and rearing children”, and “health of the children”.

Sociodemographic data included sex, education (general/technical), the occurrence of handicaps or genetic diseases in their family, whether they have contact with people with a handicap or a genetic disease in their environment, and religious practice (not religious/religious and rarely attending church/religious and quite regularly attending church/religious and very frequently attending church). In Flanders, religious people are mostly Roman Catholic.

The relationship between the variables mentioned was studied by means of the Kendall rank correlation coefficient (tau). Only the significant associations (p<0.05) will be mentioned in the results section.

Results

ATITUDES TOWARDS GENETIC INFORMATION, PRENATAL DIAGNOSIS, AND PREGNANCY TERMINATION

About 17% of the sample (table 1) replied that they would certainly seek information about genetic risks before pregnancy and 39% said they would probably do this. During the interview, the majority of the subjects gave only one argument for or against information-seeking, some gave more than one, and some made no comments. The most important arguments for information seeking were: making informed decisions about reproduction (32-9% of the sample) and being better emotionally prepared for the birth of a child with a severe genetic disease or handicap (20-1%). Making informed decisions refers to expressions such as “I would take reproductive decisions on the basis of the information”, “After getting information on genetic risks, I would choose between having children or not”. The most frequently given argument against asking for information was a strong desire for children regardless of possible genetic problems (11-0% of the sample). This category covers comments such as “I want to have children anyway”, “One should accept children as they are”, “Information would have no effect on my desire for children”. Anxiety and stress about the information given was only sporadically reported as an objection (2-4%). A small proportion of the sample (7-9%) said that they did not need information because there were no genetic diseases in their family and 6-7% said that they would not think about such matters at the moment of making reproductive plans. Nearly 13% of the sample claimed that their future information seeking would depend on the presence or absence of genetic disease in the family.

About 18% of the sample (table 1) asserted that they would like to have prenatal diagnosis and 44-5% said that they probably would use it. The free comments during the interview showed that being better prepared for the birth of a child with serious problems was the most frequently given argument (39-6%) in favour of prenatal testing. Making informed decisions about pregnancy termination was the second most important argument (mentioned by 21-3% of the sample). About 7% said they would like to have a prenatal diagnosis so that special treatment of the newborn baby could start in time. Reluctance for abortion was the most important objection against prenatal diagnosis. Anxiety about the result of prenatal testing was mentioned by 4-9% of the sample. This anxiety category covers comments such as “Knowing that I am pregnant with a child with a serious handicap would be too stressful”. Eleven percent claimed that their use of prenatal diagnosis would depend on the presence of genetic disease in the family.

The attitudes towards pregnancy termination in the three hypothetical situations are also presented in table 1. Only a minority of the adolescents answered that they would want a termination. The spoken comments on pregnancy termination showed that a large proportion of students (43-4%) claimed that pregnancy termination should only be allowed for “serious reasons”: “if the mother’s life is in danger”, “if the mother has been raped”, “if the mother is only 17 years old”, “if the fetus has a serious handicap”, “if the child would suffer too much”, “if the child would die soon”, … Sixteen percent of the students rejected abortion completely (“A child with a severe handicap also has a right to live”, “Abortion is murder”, …). A subgroup of the sample (8-4%) spontaneously added in their spoken comments that a pregnancy termination should be the decision of the parents and not of a third party.

CORRELATIONS OF ATTITUDES AND SOME RELEVANT VARIABLES

A positive attitude towards health related prevention in general, measured by the EHBS...
for a genetic disease. We found no significant associations of these perceived feelings with the attitudes to genetic information and counselling.

None of the questions about the perceived susceptibility correlated significantly with the students’ attitudes. Table 2 presents the distribution of the responses. A salient finding was that the frequency distribution of their own risk significantly shifted to the lower risk categories, compared with the risk distribution for a random couple (sign test; z = 5·65, p<0·0001).

Table 3 presents the opinion of the students about the preventive role of society. Nearly 40% of those who agreed with the first statement added that providing information about genetics is important, although the decision about what to do with this information should not be influenced by society. With regard to the second statement, the only comment of those agreeing was that asking a doctor for information about genetic risks was important but that society should not restrict the free choice of the couple (44·5% of 108 persons). Agreeing with stimulating young couples to seek information about increased genetic risks as being a task of society (statement 2) was significantly associated with the personal intentions to ask for information about increased genetic risks before making reproductive decisions (tau = 0·24, p<0·001).

Table 4 presents the mean scores for the importance of seven values. Both values concerning health, own health and that of the children, attained the highest means and the lowest dispersion. The more they were in favour of asking for information before making reproductive plans and of asking for prenatal diagnosis, the higher they valued “own health” (tau = 0·18, p<0·01 and tau = 0·13, p = 0·05). Neither “health of the children” nor other values correlated significantly with personal intentions.

The personal intentions of the students were associated with neither the occurrence of handicaps or genetic diseases in the family (according to the birth of a child with a severe mental handicap, 5·5 (SD 1·2) for the birth of a seriously physically handicapped child, and 5·9 (SD 1·0) for the birth of a child with a severe genetic disease. Significant correlations with personal intentions were found: the more they claimed to be in favour of prenatal diagnosis, the higher they perceived the burden of the birth of a child that would be seriously mentally retarded (tau = 0·25, p<0·001), of the birth of a child with a severe genetic disease (tau = 0·14, p<0·05). Opting for pregnancy termination was more likely to correspond to a higher perceived burden of having a child with a mental handicap (tau = 0·18, p<0·01), with a physical handicap (tau = 0·19, p<0·01), or with a genetic disease (tau = 0·21, p<0·01).

The mean item score on the HOS (perceived self-concept of a person with a handicap) was 3·1 (SD 0·6) for mental handicap, 2·6 (SD 0·6) for physical handicap, and 2·5 (SD 0·5)

(mean item score = 6·8, SD 1·3), was significantly correlated with personal intentions regarding asking for information before pregnancy (tau = 0·16, p<0·01) and regarding making use of prenatal diagnosis (tau = 0·13, p = 0·05). We found no significant associations between basic genetic awareness and the adolescents’ attitudes towards genetic information and tests. The mean knowledge score on the 10 multiple choice items was 3·2 (SD 1·7).

The mean perceived parental burden was 6·1 (SD 1·0) for the birth of a child with a severe mental handicap, 5·5 (SD 1·2) for the birth of a seriously physically handicapped child, and 5·9 (SD 1·0) for the birth of a child with a severe genetic disease. Significant correlations with personal intentions were found: the more they claimed to be in favour of prenatal diagnosis, the higher they perceived the burden of the birth of a child that would be seriously mentally retarded (tau = 0·25, p<0·001), of the birth of a child with a severe genetic disease (tau = 0·14, p<0·05). Opting for pregnancy termination was more likely to correspond to a higher perceived burden of having a child with a mental handicap (tau = 0·18, p<0·01), with a physical handicap (tau = 0·19, p<0·01), or with a genetic disease (tau = 0·21, p<0·01).

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Discussion

Spontaneous beliefs and opinions of adolescents about genetic disease, genetic risk information, and genetic testing have received little attention in the past. In the present study these opinions were elicited in the context of a structured face to face interview about health and prevention, partly including genetic disease. The design of the study, standardised questionnaires embedded in an interview, allowed the adolescents to express fully their beliefs, comments, and concerns in a situation of personal contact with a psychologist of the Centre of Human Genetics in Leuven.

The results show that more than half of the students said that they were interested in information about genetic risks before reproduction, so that they would probably or certainly ask a doctor for more information. One third argued that this information would give them the opportunity to make informed decisions about having children or not. Another benefit was being better emotionally prepared for the birth of an affected child. Eleven percent of the adolescents mentioned that they wanted children anyway, regardless of possible genetic risks; they used this as an argument against seeking information about genetic risks. A more positive attitude towards information seeking before reproduction was significantly associated with a more favourable attitude towards prevention of health problems in general and with valuing their own health higher. It is intriguing that we did not find a significant correlation with the value ‘health of the children’.

Sixty-three percent of the students said that they would consider prenatal testing during pregnancy. Being emotionally better prepared for the birth of an affected child, not preventing its birth, was the most important argument. Only one in five adolescents would make use of prenatal diagnosis to decide about pregnancy termination. Evers-Kiebooms et al. reported that prenatal testing would be certainly or probably used by three quarters of a sample of 385 adults in the general population in a hypothetical situation of a 25% risk for having a physically or mentally handicapped child. The less positive attitude towards prenatal diagnosis in the group of adolescents may be partly because of the difference in phrasing of the questions. We found significant associations with the attitude towards health related prevention in general, with perceived parental burden of the birth of an affected child, and with the value ‘own health’.

The attitudes towards pregnancy termination in the three hypothetical situations showed a reluctance for it. The students emphasised in their free comments that it should only be allowed for “serious” reasons, such as danger to the mother’s life, rape, too much suffering of the child, or a “serious” handicap of the fetus. At their age, lack of experience of life may lead to weighing up the severity and burden of various conditions. However, in the context of this study, their subjective interpretation is more important. It is obvious that different adolescents might have completely different conditions in mind when they gave an answer about “a serious handicap”. The main point of interest, however, is their subjective perception of a serious situation. The students seemed to realise that there are serious and less serious indications for abortion. These findings suggest that they develop a critical attitude when confronted with information about genetic diseases and genetic counselling, which is an important condition to be fully aware of the psychological and ethical issues connected with genetic technology. Adults showed a less negative attitude towards abortion than adolescents. About 40% of the sample of the study of Evers-Kiebooms et al. would consider pregnancy termination if the child would be mentally handicapped and 17% would consider it for a physically handicapped fetus. Green et al. questioned 1757 women booking for antenatal care in Britain, found that 66% would consider an abortion should there be “a strong chance that the baby will be handicapped”. Another interesting finding was that young women were more opposed to abortion than older women. These and other studies in the general population showed a discrepancy between acceptance of prenatal testing and pregnancy termination. In the present study this discrepancy is even more pronounced and may be because of the lack of life experience of the students as well as their different spontaneous view on the purpose of prenatal testing, namely being prepared for the birth of an affected child, rather than preventing its birth. This should be taken into account when setting up an information campaign for young people. Too strong an emphasis on pregnancy termination after prenatal diagnosis may induce an aversion towards genetic information and genetic counselling, which may compromise their future information seeking about genetic risks.

For each of the three hypothetical situations, intentions concerning prenatal testing and pregnancy termination were correlated with the perceived parental burden of the birth of a seriously affected child, and not with the perceived feelings of the child. The latter finding is intriguing because suffering of the child was spontaneously mentioned as a reason to choose pregnancy termination.

Awareness of basic genetic concepts was poor. About half of the students perceived the risk of having a child with a serious genetic disease or congenital malformation to be between 1 and 5%. The others clearly underestimated or overestimated the risk. The students had on average a more optimistic view of their own genetic risk than of the risk of a random couple: the perceived susceptibility to the birth of a baby with a serious congenital problem shifted significantly to lower risk figures when estimating their own risk, compared
with the estimation of another’s risk. This phenomenon is called unrealistic optimism, which is often observed in various risk situations.  

It should be taken into account when organising educational programmes, since it may withhold people from seeking or recording information which may be relevant for them.

The students hold the conviction that society should play a role with regard to these issues. Providing information about genetics in general and promoting information seeking about genetic risks before reproduction were considered as acceptable tasks for society, with the important condition that society should not impose what one should do with this information.

The fact that the two questions about the role of society immediately elicited many remarks concerning the autonomy of the individual person may be the result of an ambiguity in the phrasing of the statements. The actual presentation did indeed not offer the opportunity to endorse a positive statement about the state not having a preventive role and respecting the freedom of the individual. Agreeing with the statement implied a double agreement, namely agreeing that society has to prevent the birth of a seriously handicapped child as well as agreeing about the means to achieve this. It is clear from their reactions that students want to be free to decide what they want to do with the information they receive; they do not want to be obliged by society to “prevent” the birth of an affected child. The autonomy of the individual person is indeed essential in clinical genetics. An information campaign concerning human genetics aimed at increasing knowledge should therefore explicitly address the issue of the freedom of the individual person with respect to reproductive decisions making and genetic testing.

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