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Minors and informed consent in carrier testing: a survey of European clinical geneticists

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ABSTRACT

Purpose: A study was made of attitudes of clinical geneticists regarding the age at which minors should be allowed to undergo a carrier test and the reasons they provide to explain their answer.

Methods: European clinical institutions where genetic counselling is offered to patients were contacted. 177 (63%) of the 287 eligible respondents answered a questionnaire.

Results: Clinical geneticists were significantly more in favour of providing a carrier test to a younger person if the request was made together with the parents than if the adolescent requested the test personally. Although a large fraction of respondents (16%–30%) were “neither unwilling nor willing” to provide a carrier test to a 16-year-old adolescent who requested the test personally, for most disorders slightly more clinical geneticists were “very willing” or “willing”.

Conclusion: Age is not the only decisive element when considering the participation of adolescents in decisions affecting their health. The clinical geneticists referred to cognitive, emotional and sexual maturity and the support of parents as crucial elements in their comments regarding when to tell children about their genetic risk or to allow adolescents to request a carrier test.

Carrier testing is performed to determine whether an individual carries a mutated gene or balanced chromosomal rearrangement and is relevant for autosomal recessive and X linked disorders and for chromosomal abnormalities. In a previous article¹ we analysed how 14 different guidelines and position papers discussed carrier testing in minors. We reported that all guidelines were in agreement that ideally minors should not undergo carrier testing. As such testing can affect a minor's future reproductive prospects, the guidelines have emphasised that the decision regarding a carrier test should not be made by the parents on behalf of their children, but should be made by the children themselves when they reach reproductive age. The position is based on the absence of medical benefit in providing this test before reproductive age, on respect for the individuals' freedom and on the fact that children should be able to provide freely and voluntarily, without external pressure, their consent to be tested after being informed of the benefits, risks, procedures and other pertinent information relating to the carrier test.

Although clinical-ethical guidelines agree that carrier testing should preferably be delayed until minors can decide for themselves whether and when to undergo the test, the guidelines^{1–2} for the most part do not provide age-related recommendations regarding when adolescents might be able to

request a carrier test themselves, with or without their parents. Most guidelines recommend that age should be given flexible consideration. The Working Party of the Clinical Genetics Society (UK) recommended that testing should be deferred “until the child is able to understand the issues and requests for testing in person”.³ American recommendations emphasised that adolescents should meet “conditions of competence, voluntariness, and adequate understanding of information”⁴ and have “decision making capacity”.⁵ The opinion of the German Society of Human Genetics recommends testing only when the minor “can understand all the associated facts and psychosocial implications and asks for the test him/herself”.⁶ The German opinion reports that, as a general rule, an adolescent can be expected to have this ability at the age of 18 years.

We studied the attitudes of clinical geneticists regarding the age at which minors should be allowed to undergo a carrier test and the reasons they gave to explain their answers. Until now, as far as we know, no research has analysed these questions.⁷ Most of the existing studies^{8–9} were performed when professional recommendations on the issue had just been published and might therefore not have been translated into practice at the time of the research. Another relevant and recent study¹⁰ was only a pilot study, including a group of respondents composed of only 12 pediatricians and 13 geneticists. Finally, the European perspective of our study complements a recent one that examined the current practices and attitudes of American and Canadian genetic service providers regarding testing adolescents for carrier status.¹¹

METHODS

Procedure

With the help of the website orphanet (<http://www.orpha.net>), the websites of the national genetic associations and/or national contact persons, we drew up a list of 312 clinical institutions in the 27 European Union member states at which genetic counselling is offered to patients, omitting institutions providing only laboratory services or only prenatal diagnosis. The head (usually) of each institution was contacted, with the aim of receiving a questionnaire back from every institution. Medically qualified specialists in genetics who had offered genetic counselling to patients in the past year were asked to complete a survey of items assessing their attitudes and practices regarding genetic testing in minors. (In the rest of the article we will refer to them as clinical geneticists.) Every questionnaire contained a list of the institutions

that had been identified in their country, and respondents were asked if they knew other institutions in their country that were not listed there. The data were collected between October 2006 and March 2007. Two weeks after the questionnaires were sent out by email, a reminder was sent to non-responders. Second, third, fourth and sixth reminders were sent by email at intervals of about 2 weeks. The fifth reminder was sent by post. No monetary or other incentive was offered.

Statistical analysis

Because the samples did not meet the assumptions for normality, a two-tailed Mann–Whitney U test was used to compare differences in answers between men and women, and between younger (less than 50 years) and older clinical geneticists (50 years or older). Differences at a 0.05 level were considered significant. Content analysis of the open-ended questions was used to analyse the answers of the respondents. The content analysis resulted in the creation of a number of conceptual categories that are relevant when making a decision about whether or when to provide a carrier test to an adolescent.

RESULTS

Sample

Five supplementary institutions were identified thanks to the respondents. Of the 317 institutions we contacted, 17 responded that they were only providing laboratory services or prenatal diagnosis or had ceased their activities. Fourteen others were excluded for the same reason, but on the indication of another respondent. Five institutions were excluded because the staff member who responded to the questionnaire answered in the name of two institutions. Of the remaining 281 eligible institutions, 177 (63%) returned a completed questionnaire. The mean year of birth of the clinical geneticists who answered the questionnaire was 1956 (SD 8.7; range 1934–1977); of these 177 respondents, 47% were women. We received responses from 26 European countries (table 1).

Attitudes

As reported in table 2, the clinical geneticists answered that on average they would “recommend parents to tell their children of their genetic risk of carrier status” at the age of 15.66 years (SD 2.36). To the question “from what age do you think minors should be allowed to request a carrier test if their parents consent to the test”, the mean response was 15.97 (SD 2.16) years. To the same question, but now “without the consent of their parents”, the mean response was 16.89 (SD 1.43) years. The Mann–Whitney U test indicated that the clinical geneticists significantly favoured providing a carrier test to a younger person if the request was made together with the parents of the adolescent ($z = -4.4854$, $p < 0.001$). Gender and age did not affect the responses. The UK reported the lowest average ages for all questions.

Diseases

Table 3 presents the clinical geneticists’ willingness to provide a carrier test to a 16-year-old minor whose parents are both carriers and who is requesting the test personally. Quite a few respondents answered that they were “neither unwilling or willing” (range 16%–30%). For most disorders, slightly more clinical geneticists were “very willing” or “willing”.

Arguments used

The answers of the respondents show that stating a specific age at which minors should be told about their genetic risk for carrier status or should be allowed to request a carrier test is very difficult and for some clinical geneticists even impossible. Therefore, some refused to state a specific age. As a respondent expressed it, “In fact, it is impossible for me to indicate a specific age.” Another wrote, “There is no such age as one age at which testing is acceptable, this can vary, that is what counselling is all about.” On the basis of a content analysis of the answers, we identified the following elements that respondents took into consideration when deciding whether to inform a minor about the genetic risk or to allow a carrier test: cognitive maturity, emotional maturity, sexual maturity, the support of parents, age (adulthood) and national legislation.

Cognitive maturity

Cognitive maturity emerged as an important factor regarding the decision to inform minors about their genetic risk or to allow carrier testing, with or without parental support. As expressed by a clinical geneticist who would allow a carrier test in a 14-year-old minor, “The children today have mostly good education and information about genetics and they are developed enough to have such informations.” Another clinical geneticist referred to the correct “understanding of the genetic term carrier” as an important factor in the decision-making. Another wrote, “The age of the child cannot determine whether a child can consent to be involved in tests for their genetic status or genetic counselling. It belongs to the intellectual status of the child, not the age. They must clearly understand what happens and what are the possible results of the test. They must clearly know what decisions they take.”

Emotional maturity

Emotional maturity was found to be an important element in the decision-making process of these clinical geneticists. They emphasised that minors should have “mental competence” or “an emotional maturity”. This includes the preference that minors should “be mature enough to understand and to bear this information”, “have the resources to cope with the result”, have “the ability to foresee problems/consequences of testing after genetic counselling” and be able to “appreciate the concept of risk”. A respondent wrote that minors should have a “plenary understanding and maturity”, which was expected by this respondent at 18 years of age. Another reported that “usually minors of 17 years are not mature enough to accept such information.”

Sexual maturity

Many respondents referred to sexual maturity as an important reason for allowing carrier testing in minors. However, there was clear disagreement about the age at which sexual maturity is relevant. Some clinical geneticists would allow such testing in minors as soon as they have “maturity for reproduction” (from 12 years on). Some referred to the risk of unplanned pregnancy as an important reason to allow carrier testing at a young age: “the increase in teen pregnancies even as young as 13 years”. Other clinical geneticists referred to the age of 15 years: “In my opinion until they are 15 years old it is not important for them to know their carrier status and probably they wouldn’t understand it. From 15 years of age they can have their own children and they should be allowed to request a carrier test.” For other respondents, the argument of “reproductive age” is

Table 1 European institutions of clinical genetics responding to survey

Country	No. responding (per cent of total responses)
Austria	4 (2.26)
Belgium	6 (3.39)
Bulgaria	2 (1.13)
Cyprus	1 (0.56)
Czech Republic	6 (3.39)
Denmark	2 (1.13)
Estonia	1 (0.56)
Finland	6 (3.39)
France	23 (12.99)
Germany	23 (12.99)
Greece	3 (1.69)
Hungary	9 (5.08)
Ireland	1 (0.56)
Italy	28 (15.82)
Latvia	1 (0.56)
Lithuania	2 (1.13)
Malta	1 (0.56)
Poland	8 (4.52)
Portugal	4 (2.26)
Romania	2 (1.13)
Slovakia	6 (3.39)
Slovenia	1 (0.56)
Spain	11 (6.21)
Sweden	4 (2.26)
The Netherlands	5 (2.82)
United Kingdom	17 (9.60)

considered relevant only at 18 years. The minors “can make an own decision properly at that age [18 years] and might start to think about family planning”. A clinical geneticist referred to ethnical motivations in this context: “only in certain (ethnical) circumstances when early marriage is planned, otherwise after 18”. Furthermore, some clinical geneticists reported being more open to allowing a test for girls at a younger age—for example, “we would usually suggest offering testing at around 14 in a girl but judge this to depend of the girl’s maturity.”

Parental support

The support of the parents was considered an important reason. Minors requesting a test with their parents could expect more support from the clinical geneticists than minors without their parents. As expressed by one respondent, “If the minors have the parent’s consent, I don’t find any problem.” Parents are also considered by some clinical geneticists to be the persons who know their children best: “Parents in general know if their child is mature enough to undergo the test.” Some clinical geneticists consider it unwise not to include the parents in the decision: “It will create problems within the family if a minor has secrets

from parents and create conflicts if parents are legally in charge but overruled by the child.” However, the support of parents is not considered indispensable in all situations. One respondent wrote, “Parents’ consent seems me to be very important. However, in some rare cases the family history could allow children to ask for the test without the parents’ consent.” Another respondent, who also judged that parental consent is not always needed when testing adolescents, wrote, “In some families, there are communication problems: a specific family dynamics which make difficult to ask for consent”.

Age

Some respondents recommend that carrier testing should be postponed until adulthood because of the impact such information can have on an adolescent. A respondent emphasises the “sensitivity of the time period in the development of an individual to any information which is not needed but could be traumatising and falsely interpreted.” Another clinical geneticist recommends “not to disturb the child far from parentality”.

National legislation.

Many respondents refer to national law as a guide in decision-making. For example, a Danish respondent referred to national rules: “According to Danish law, the patient can decide about his own health from 15 years of age.” An Italian respondent wrote, “Parental jurisdiction holds until 18 years in our country. Before this age, the issue should be discussed and shared with the parents.” Some respondents did not know their national law. A Portuguese respondent wrote that in Portugal “minors are allowed to decide by themselves in some issues from the age of 16”. In reality, in Portugal minors are allowed to take healthcare decisions autonomously from the age of 14, based on article 38.3 of the Portuguese Criminal Code. A respondent of the Czech Republic refers to “the Czech law—18 years is the adulthood in CZ [Czech Republic], this is the official limit which I have to recommend.” Although the legal age is 18 years in the Czech Republic, according to article 9 of the Czech Civil Code, whether a minor is capable of taking healthcare decisions autonomously has to be evaluated on a case-by-case basis and depends on the seriousness of a medical intervention.¹² A Danish respondent wrote: “Danish law states that a child of 15 years should be informed about and consulted in questions concerning his or her health.” However, according to article 15¹ of the Health Act 2005, not only should minors be informed and consulted, but from age 15 they are allowed to take healthcare decisions autonomously after having informed the parents and after having involved them in the decision.¹³ Finally, a Spanish respondent wrote: “For legal reasons in Spain, one is minor until 18. Exception, if he/she or the partner is pregnant.” According to article 9.3.c of the Spanish patient rights law of 2002, however, “in the case of minors who are neither incapable nor incapacitated, but emancipated or have reached their sixteenth birthday, then consent by representation cannot be granted.”

Table 2 Clinical geneticists’ responses regarding age at which they would provide information about risk of genetic carrier status to minors

Question	Mean (SD) age (years)				
	Whole sample	France	Germany	Italy	United Kingdom
In general, from what age on do you recommend to tell their children of their genetic risk of carrier status?	15.66 (2.36)	15.59 (1.58)	15.37 (2.65)	16.64 (1.22)	13.15 (2.70)
In general, from what age on do you think minors should be allowed to request a carrier test if their parents consent to the test?	15.97 (2.16)	16.42 (1.35)	16.39 (1.07)	15.68 (3.15)	14.07 (1.44)
In general, from what age on do you think minors should be allowed to request a carrier test on their own without the consent of their parents?	16.89 (1.43)	16.95 (1.31)	16.76 (1.18)	17.38 (0.94)	14.79 (1.42)

Table 3 Willingness of clinical geneticists (whole group or from only some countries) to provide a carrier test to (A) a 16-year-old minor whose parents are both carriers of an autosomal recessive disorder or (B) a 16-year-old girl whose mother is a carrier of an X linked disorder

Disorder	Per cent (No./total responding)				
	1. Very unwilling	2. Unwilling	3. Neither unwilling or willing	4. Willing	5. Very willing
(A) Autosomal recessive					
α -1-Antitrypsin deficiency	7 (11/162)	28 (46/162)	20 (33/162)	37 (60/162)	8 (12/162)
Deafness (connexin 26)	9 (14/166)	28 (47/166)	19 (32/166)	37 (62/166)	7 (11/166)
Aspartylglucosaminuria	9 (14/150)	31 (46/150)	25 (38/150)	32 (47/150)	3 (5/150)
Sickle cell anaemia	8 (12/156)	26 (41/156)	21 (33/156)	40 (62/156)	5 (8/156)
Ataxia telangiectasia	11 (17/158)	30 (48/158)	22 (35/158)	33 (52/158)	4 (6/158)
Spinal muscular dystrophy	9 (15/165)	25 (42/165)	21 (34/165)	39 (64/165)	6 (10/165)
β -Thalassaemia	7 (12/159)	27 (43/159)	21 (33/159)	39 (62/159)	6 (9/159)
Tay-Sachs disease	10 (16/153)	28 (43/153)	19 (29/153)	37 (56/153)	6 (9/153)
Cystic fibrosis	8 (13/170)	26 (44/170)	16 (28/170)	42 (71/170)	8 (14/170)
(B) X linked					
Adrenoleucodystrophy	7 (11/164)	26 (42/164)	22 (37/164)	40 (65/164)	5 (9/164)
Glucose-6-phosphate dehydrogenase deficiency	5 (8/160)	28 (45/160)	22 (35/160)	39 (63/160)	6 (9/160)
Choroideremia	6 (9/150)	26 (39/150)	26 (39/150)	38 (57/150)	4 (6/150)
Haemophilia A	5 (8/166)	22 (37/166)	23 (38/166)	42 (69/166)	8 (14/166)
Fabry disease	6 (10/156)	24 (38/156)	20 (31/156)	44 (69/156)	6 (10/156)
Retinitis pigmentosa	6 (10/161)	27 (44/161)	21 (34/161)	41 (65/161)	5 (8/161)
Fragile X syndrome	5 (8/168)	22 (37/168)	18 (31/168)	48 (80/168)	7 (12/168)
X linked severe combined immunodeficiency	6 (10/158)	25 (40/158)	30 (32/158)	41 (65/158)	7 (11/158)

The minor is requesting the carrier test personally.

DISCUSSION

Medical treatment can be carried out only when a patient has been informed of the purpose, nature, risks and consequences of the intervention and has freely consented to it. A health intervention on individuals who are not able to exercise their right to autonomy in a healthcare setting due to their age, as in the case of minors, or their mental capacity, may be carried out only with the authorisation of their representative as provided by law. However, in Europe, national legislation regarding the legal position of minors in a healthcare setting varies greatly from country to country.¹⁴ In many countries the age at which healthcare decisions may be taken autonomously is fixed at 18 years, which corresponds to the age of legal majority. This is the case in, for example, Austria, Italy, Greece, Slovakia and Poland. In contrast, various countries have opted for a lawful decision-making capacity in healthcare matters below the age of legal majority. Portugal fixed the age at 14 years, Denmark and Slovenia at 15, and Spain at 16. Other countries, such as the Czech Republic and Estonia, have opted for a flexible system in which it should be evaluated on a case-by-case basis whether a minor is capable, according to age and maturity, to take healthcare decisions autonomously.

In a country such as the UK, where the age of medical majority is below the age of legal majority, the respondents were clearly willing to provide a carrier test to adolescents on their personal request at a younger age than in other countries where the age of medical majority equals the age of legal majority. In the UK, the Family Law Reform Act states that adolescents between 16 and 18 years of age are presumed to be competent to give consent without any necessity to obtain consent from parent(s) or guardian(s). Furthermore, the common law, under the influence of the Gillick case, rejects the position that consent from parents is always needed before treating minors younger than 16 years. When a young person who has sufficient understanding and intelligence to understand fully what is proposed consents to treatment, parental consent is not legally necessary, although parental involvement

is mostly encouraged. Therefore, it is not surprising that UK-based clinical geneticists thought that minors should be allowed to request a carrier test on their own without their parents' consent at a mean age of 14.79 years. In countries such as France and Italy, where the age of medical majority equals the age of legal majority, geneticists were of the opinion that a carrier test may be provided to adolescents on personal request at a mean age of 16.95 and 17.28 years, respectively. These results seem to indicate that various clinical geneticists in France and Italy are willing to allow minors who are younger than 18 years but are capable of a reasonable judgement of their interests to take health decisions autonomously. Although French law contains a specific provision regarding mature minors, these minors are allowed to take healthcare decisions only together with their parents. On the basis of our data, some clinical geneticists seem to be willing to provide a carrier test to minors without the consent of the parents, which is not in keeping with French law. It was also remarkable that some clinical geneticists did not know the applicable legal regulations. For example, although in some countries minors are legally allowed to request such a test without the consent of their parents, some clinical geneticists in those countries would deny a carrier test to a minor.

The support of the parents in an adolescent's request for a carrier test is considered by most clinical geneticists to be an important element in the consideration of the request. We found that the clinical geneticists were significantly more in favour of providing a carrier test to a younger person if this request was made together with the the parents. This is in line with previous recommendations,¹ which underline the familial character of genetic information and emphasise that genetic risk information should be discussed as openly as possible in a family context.¹⁵ It has been stressed that parents are responsible for the health and well-being of their children and have an important responsibility to communicate the genetic risk to their children and to support them in dealing with that risk.¹ However, together with this family approach, the individual character of this information, the individual decision

to undergo a genetic test and the individual choice to share the result of the genetic test with others has always been advanced.¹⁶ The application of ethical principles to genetic services has urged a particular attention to respect for autonomy, privacy and confidentiality. In the absence of a medical reason to perform carrier testing, minors are entitled to these rights.¹

Some evidence suggests that although parents are the best placed to inform their children of their genetic risk, some parents decline to tell them, defer disclosure of genetic risk or encounter difficulties in telling them.¹⁷ Furthermore, some studies have reported that some parents continue to have difficulties with the information about the carrier status in their children. Some parents might even make erroneous assumptions regarding carrier status and initiate a socialisation of the child into a sick role.¹⁸

Telling children about genetic risk is generally seen as a parent's responsibility,¹⁷ but health professionals may be needed in a supporting role. The response of the clinical geneticists regarding the age at which they would recommend parents to tell their children about their genetic risk of carrier status was higher than expected (mean 15.66 years). Also the fact that some clinical geneticists referred to the fact that information about risk of carrier status should preferably be told later in life, because telling too early "could be traumatising and falsely interpreted", was surprising. In the literature, various authors^{19–20} had indeed described that it is important to tell children gradually as soon as the opportunity presents itself or when questions arise. In this way, children can also incorporate that knowledge gradually and integrate it in their developing self-identity. The Canadian Paediatric Society, for example, stated that "as early as four years old, children understand some concepts of inheritance" and that "concrete concepts of health-related procedures are generally developing by age seven years", while a "full understanding of the nature and consequences of agreeing to or refusing medical management does not occur until early adolescence, and maybe later."²¹ Although we found in our survey, as well as in another recent study,¹¹ statements and responses that are opposed to the idea of identity development and adjustment time,^{22–23} this might also be explained by different interpretations of the question we asked in the survey. We did not ask the respondents at what age the parents should tell their children *for the first time* about their genetic risk for carrier status. Therefore, respondents might have experienced this question as a question about when the children are ready to hear about the existence of a carrier test that might inform them about their potential carrier status. It is a different question to consider the moment when children can learn about their genetic risk and when they can learn about a carrier test in which they can actually know if they are really at risk.

CONCLUSIONS

Age is not the only decisive element when considering the participation of adolescents in decisions affecting their health. The clinical geneticists in our survey considered cognitive, emotional and sexual maturity, as well as the support of parents, to be crucial elements in the decision as to when to tell children or to allow adolescents to request a carrier test. Parental support has been considered an important factor in allowing carrier testing to be performed at an earlier age. The

fact that age is not the principal element in the decision of clinical geneticists is made very clear by the willingness of clinical geneticists in some countries (such as France) to provide carrier tests to mature adolescents without the consent of their parents, which is against the law. In the UK, clinical geneticists showed more openness to providing a carrier test on the request of an adolescent at a younger age than in other European Union member states. This might partly be explained by the existing regulatory framework in the UK.

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