

# Psychiatric Genetic Testing: Attitudes and Intentions Among Future Users and Providers

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Psychiatric genetic research may eventually render possible psychiatric genetic testing. Whereas all genetic knowledge has certain characteristics raising ethical, legal, and social issues, psychiatric genetic knowledge adds more controversial issues. Ethical principles have been proposed as a guide in this field, but the optimal utilization of genetic testing has also been recognized to depend on knowledge of the potential consumers' attitudes. To provide knowledge to inform the public debate on mental illness and genetics, and the future conducting of psychiatric genetic testing and counseling, we surveyed attitudes toward psychiatric genetic testing among 397 patients with a psychiatric diagnosis, 164 of their relatives and 100 medical and psychology students. The results showed widespread interest in psychiatric genetic testing of self and child, but less support for prenatal testing. Psychiatric and somatic genetic testing attracted the same amounts of accept. General attitudes toward access to psychiatric genetic testing and information revealed substantial support for bioethical principles of autonomy and privacy. However, questions describing more specific situations revealed contradictions mirroring the bioethical dilemmas recognized in the field and variations in attitudes between groups with different levels of knowledge of genetics, different kinds of experience with mental illness, and different motives and preconceptions regarding psychiatric genetics. The contradictions and differences in attitudes among possible future users and providers of psychiatric genetic testing and counseling indicate ambivalence, insecurity, and perceived lack of knowledge in relation to psychiatric genetics. These results should inform further research and the future integration of psychiatric genetics into practice.

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**KEY WORDS:** ethics; genetic counseling; mental illness; genetic testing; attitudes

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## INTRODUCTION

Great hopes have been attached to genetic research into mental illness, both in relation to the goal of better treatment and prevention [Craddock and Jones, 2001; Insel and Collins, 2003], and in relation to the anticipated de-stigmatizing effect of attributing mental illness to biological causes [Phelan, 2002]. As we are waiting for these expectations to be met, we can consider the future application of psychiatric genetic knowledge into practice.

The etiology of most major psychiatric disorders is believed to be polygenic and multifactorial [Farmer and Owen, 1996], complicating both the research seeking to identify risk genes and the future interpretation of genetic test results. Furthermore, the field is burdened by the history of eugenics [Gottesman and Bertelsen, 1996; Propping, 2005] and the stigmatizing aspect of the disorders in question. Psychiatric genetics raises major ethical, legal, and social issues as pointed out by the Nuffield Council on Bioethics [1998]. Whereas this report took a rather conservative stance, discouraging testing on the basis of the poor clinical validity and the risk of negative side-effects such as discrimination, there is still a reason to believe that the identification of genes predisposing to mental illness may lead to the development of pre-symptomatic and prenatal tests [Craddock et al., 1999], even though the clinical/predictive validity of these tests may be doubtful and better treatment or prevention is still not an option. Direct-to-consumer genetic testing via the Internet may even become available in the field of psychiatry in the near future [Austin, 2006]. As psychiatric genetic testing may have other than clinical implications, we can benefit from considering these implications in advance of testing becoming an option.

Genetic knowledge has certain characteristics, influencing the application of genetic testing for all diseases: genetic knowledge involves not only one but groups of related individuals. Genetic knowledge will typically be knowledge of a risk, not certain knowledge. Genetic knowledge will often be pre-symptomatic, forcing individuals to make decisions regarding health and lifestyle even before the appearance of any symptoms. These characteristics count for all genetic knowledge, as does the risk of genetic knowledge being stigmatizing [Chapple et al., 1995], but psychiatric genetics may amplify concerns inherent to genetic knowledge. Mental illness involves, to a larger extent than somatic illness, capacities relevant to a person's identity. Psychiatric genetic information may raise questions about an individual's personal autonomy and ability to function as a rational person. Besides, but not separate from this, mental illness is associated with considerable stigma and feelings of shame and guilt. Furthermore, the coupling of genetics and mental illness raise concerns about a new eugenics. All of these characteristics highlight the issue of access to and possible misuse of genetic information [Nuffield Council on Bioethics, 1998]. These

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ethical, legal, and social issues will be present in psychiatric genetic counseling [Tsuang et al., 2001].

Ethical principles have been described as a guide to the field of biomedical ethics [Beauchamp and Childress, 1979; Knoppers and Chadwick, 1994; Rendtorff and Kemp, 2000], but a need for knowledge of the attitudes toward genetics among specific affected subgroups has also been recognized. Several authors have pointed out that the optimal utilization of genetic testing depends on knowledge of the potential consumers' attitudes [Hietala et al., 1995; Hodge, 2004; Gollust et al., 2005]. In addition, knowledge of the different health care professionals' attitudes is of importance, since they may function both as gatekeepers in relation to application of genetic knowledge [Toiviainen et al., 2003] and as future providers of genetic testing and counseling.

A large body of research has revealed attitudes toward and experience with genetic testing and counseling for specific monogenic and multifactor somatic diseases [Evers-Kiebooms et al., 2000; Henneman et al., 2001; Lerman and Shields, 2004]. This research has dealt with issues raised by genetics and is applicable to the field of psychiatric genetics, but psychiatric genetics raises additional concerns. Few studies have investigated attitudes toward psychiatric genetics, focusing on attitudes toward psychiatric genetic testing [Smith et al., 1996; Trippitelli et al., 1998; Jones et al., 2002] and even fewer have been concerned with how persons suffering from mental illness and their relatives perceive the question of access to psychiatric genetic testing and information [Illes et al., 2002a; Delisi and Bertisch, 2006]. As these questions involve legal and ethical issues, the attitudes of future consumers and providers are important for the wider public debate on genetics and mental illness, for policymaking and for the future integration of psychiatric genetic knowledge into the healthcare system. This study aims at measuring the attitudes and intentions toward psychiatric genetic testing among possible future users and providers.

## MATERIALS AND METHODS

### Participants

The participants were mainly persons volunteering for different genetic projects at the Centre for Psychiatric Research at Aarhus University Hospital:

- (1) The depression network (DeNT) study with the aim of identifying genes for depression, including sib-pairs suffering from recurrent depression and their parents and healthy siblings [Farmer et al., 2004].
- (2) A study with the aim of identifying genetic and environmental causes of panic disorder, including patients with panic disorder, agoraphobia and/or social phobia, and their parents.
- (3) A study with the aim of identifying genetic and environmental risk factors for mental illness with psychotic symptoms or severe affective disorders, including patients with schizophrenia or bipolar disorder and their parents.

Six hundred eighty-one patients and relatives received the questionnaire. Of these 561 responded, giving a response rate of 82.4%. Of these 248 were diagnosed during participation in the genetic studies using the diagnostic interview SCAN 2.1 [WHO, 1998]. Diagnoses included: recurrent depression ( $n = 79$ ); bipolar I disorder ( $n = 29$ ); schizophrenia ( $n = 35$ ); panic disorder, social phobia, and agoraphobia ( $n = 105$ ). Besides these patients, we included persons not fulfilling the inclusion criteria for the DeNT study but reporting to be suffering from depression ( $n = 149$ ) and therefore included in

the group of patients diagnosed with depression; relatives of included patients ( $n = 164$ ); and medical students in their fourth year and psychology students in their second year of study ( $n = 100$ ), all recruited at Aarhus University with a response rate of 42%. A total of 661 persons were included in the study.

### The Survey Instrument

A questionnaire was developed specifically for this study on the background of (1) literature concerning ethical, legal, and social issues raised by psychiatric genetics [Nuffield Council on Bioethics, 1998], (2) existing research on attitudes toward psychiatric genetics [Smith et al., 1996; Trippitelli et al., 1998; Jones et al., 2002; Illes et al., 2002b], and (3) the results from a focus group study involving eight participants diagnosed with depression and interviewed on two occasions. A first version of the questionnaire was tested among 18 medical students, leading to revisions based on their feedback. The next version was reviewed by a psychologist and an anthropologist experienced in the survey method, and it was revised to its final version containing 100 items assessing: experience with mental illness, knowledge of mental illness and genetics, acceptance of mental illness, attitudes toward psychiatric genetic research and toward access to genetic testing and information, intentions toward testing, and attitudes toward prenatal testing and abortion. The last section of the questionnaire contained items measuring socio-demographic variables. A short description of psychiatric genetics prefaced the questionnaire. It said that psychiatric genetic research aims at identifying risk genes predisposing for mental illness; that a psychiatric genetic test will only provide information about a certain probability of developing a mental illness; and that psychiatric genetic testing is still not an option. Respondents were told to imagine, when answering the questions, that psychiatric genetic testing was an option.

### Statistical Analysis

Data analysis was conducted in three steps:

Firstly, descriptive statistics were generated to describe the study sample.

Secondly, a knowledge scale of seven questions probing the respondents' knowledge of genetics and mental illness was analyzed using item-response theory. The scale fitted a Rasch model with age and gender as exogenous variables. The scale was treated as an interval scale with values from 0 to 7. *T*-tests were used to compare the group scores.

Thirdly, univariate logistic regression was carried out comparing the answers of the groups to the questions concerning attitudes toward psychiatric genetic testing.

The statistical package STATA 9.1 was used for statistical analysis (<http://www.stata.com/>). DIGRAM was used to validate knowledge scale (<http://www.biostat.ku.dk/~skm/skm/index.html>).

## RESULTS

### Sample Characteristics

The background variables of the study sample are presented in Table I.

### Results on Knowledge

Knowledge about genetics and mental illness measured on a knowledge scale showed differences between groups, students scoring significantly higher than patients ( $t = 9.6$ ,  $P < 0.001$ ) and relatives ( $t = 9.9$ ,  $P < 0.001$ ), and patients scoring significantly higher than relatives ( $t = 2.6$ ,  $P = 0.01$ ). The same

TABLE I. Sample Characteristics

Characteristics	Patients (n = 397)	Relatives (n = 164)	Students (n = 100)
Age mean (range)	43 (18–78)	58 (29–83)	26 (21–40)
Gender (%)			
M	30	44	28
K	70	56	72
Educational level (%)			
<10 years	18	29	0
10–12 years	20	18	75
13–16 years	50	41	20
>16 years	12	12	5
Religious background (%)			
Protestant	66	78	63
Other	10	3	1
Not religious	24	19	36
Importance of religion (%)			
Most/very important	18	10	3
Moderately important	33	38	26
Not very important/not important at all	49	52	71
Knowledge score			
Mean (s.d.)	4.4 (1.5)	4.0 (1.8)	5.9 (1.0)
Treatment of mental illness (%)			
Have been hospitalized	38	6	1
Have received medical treatment	81	18	3
Have received psychotherapeutic treatment	65	15	8
Perception of mental illness (agree in %)			
Mental illness can have genetic causes (n = 461)	87	71	100
I think the mental illness in my family is hereditary <sup>a</sup>	71	46	20

<sup>a</sup>Results reported represent proportions of each group agreeing to the question. Seven percent of the patients, 6% of the relatives, and 66% of the students stated the question to be “irrelevant since there is no mental illness in my family”.

pattern showed for self-reported knowledge. A minority of 32.3% of the students, 13.2% of the patients, and 9.2% of the relatives agreed that they had sufficient knowledge about genetic testing; students reporting significantly more knowledge than patients (OR = 3.2,  $P < 0.001$ ) and relatives (OR = 4.7,  $P < 0.001$ ). All participants out of which 81.3%, significantly more patients than students (OR = 1.9,  $P = 0.02$ ), agreed that there was too little information about psychiatric genetics in the mass media.

### Results on Attitudes and Intentions

Tables II–VII present the participants' answers to statements concerning access to psychiatric genetic testing and information and intentions toward psychiatric genetic testing. The tables present the proportions (%) in each of the three groups: patients, relatives and students, answering “completely agree” or “mainly agree” to the statement and the odds ratios comparing the three groups.

#### Access to Genetic Testing and Information (Tables II and III)

Respondents (77.6%), significantly more patients than students, agreed that everybody has the right to know about their risk genes. At the same time, a total of 95.2% agreed that everybody has the right to decide that they do *not* want to know of their risk genes, and 85.5% supported the right to keep their own genetic data confidential, relatives being less supportive than students and patients.

Respondents (66.6%) agreed that everybody who wants it should have access to psychiatric genetic testing, with significantly less students than patients agreeing to this. Respondents (84.3%) agreed that members of families with psychiatric diseases should have access to psychiatric

genetic testing, whereas 14.2% of the respondents agreed that members of families with psychiatric diseases should be obliged to test for the disease. A minority opposed the possibility of psychiatric genetic testing altogether, significantly less students than patients and relatives. The same pattern appeared regarding testing for somatic disease, with no significant differences between the proportions of participants opposing psychiatric and somatic genetic testing (Table II).

A minority of 16.7% supported the passing over of information of risk status to close relatives, without the permission of the tested person. Out of the sample, 32.3%, significantly more patients and relatives than students, were supportive of the general practitioner being informed about the result of a psychiatric genetic test. Out of the total 37.5% supported psychiatric genetic testing of soldiers, 45.8% supported testing of persons occupying highly responsible jobs, 22.0% supported testing of persons wanting to adopt, and 18.9% supported testing of children given up for adoption. Students were significantly less supportive of these practices than patients and relatives (Table III).

Employers' and insurance companies' access to psychiatric genetic information (results not shown in tables) was definitely rejected. Participants (96.5%) disagreed that employers should be allowed to retrieve a psychiatric genetic certificate for a future employee, 85.1% thought so of insurance companies, and 93.9% reported to be against insurance companies being allowed to demand a psychiatric genetic test before effecting a life insurance.

#### Intentions Toward Testing (Table IV)

Significantly more patients than relatives expressed intention to test at all (OR = 1.6,  $P = 0.027$ ) and significantly more patients than both relatives (OR = 2.1,  $P = 0.001$ ) and students (OR = 2.2,  $P = 0.003$ ) wanted testing notwithstanding

TABLE II. Attitudes Concerning Access to Genetic Testing and Information (Agree in %)

Statement	Patients (p) (n = 397)	Relatives (r) (n = 164)	Students (s) (n = 100)	OR (95% CI)
Everybody has the right to know about their hereditary characters	81	76	70	r-p: 0.8 (0.4-1.4) s-p: 0.6 (0.3-0.9)* s-r: 0.7 (0.4-1.4)
Everybody has the right to decide they do not want to know about their hereditary characters	94	96	97	r-p: 1.4 (0.4-5.0) s-p: 1.8 (0.5-6.2) s-r: 1.3 (0.2-6.4)
Everybody has the right to keep their own genetic data confidential	88	77	90	r-p: 0.5 (0.3-0.7)** s-p: 1.3 (0.6-2.7) s-r: 2.9 (1.3-6.2)**
Everybody who wants it should have access to psychiatric genetic testing	70	66	54	r-p: 0.8 (0.6-1.2) s-p: 0.5 (0.3-0.8)** s-r: 0.6 (0.4-1.0)
Members of families with mental disease should have access to psychiatric genetic testing	84	84	89	r-p: 1.0 (0.6-1.6) s-p: 1.5 (0.8-3.0) s-r: 1.5 (0.7-3.3)
Members of families with mental disease should be obliged to psychiatric genetic testing	13	19	10	r-p: 1.6 (1.0-2.5) s-p: 0.8 (0.4-1.5) s-r: 0.5 (0.2-1.0)
Genetic testing for psychiatric disease should not take place	21	22	8	r-p: 1.1 (0.7-1.7) s-p: 0.4 (0.2-0.7)** s-r: 0.3 (0.1-0.7)**
Genetic testing for somatic disease should not take place	17	25	4	r-p: 1.6 (1.0-2.5)* s-p: 0.2 (0.1-0.6)** s-r: 0.1 (0.1-0.4)**

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$ .

TABLE III. Attitudes Concerning Access to Genetic Testing and Information (Agree in %)

Statement	Patients (p) (n = 397)	Relatives (r) (n = 164)	Students (s) (n = 100)	OR (95% CI)
If risk genes for mental disease are detected in a person, close relatives should be informed, even without the agreement of the tested person	18	19	12	r-p: 1.1 (0.6-2.0) s-p: 0.6 (0.3-1.2) s-r: 0.6 (0.3-1.4)
The general practitioner should be informed about the results of a psychiatric genetic test, with or without the patients consent	37	39	14	r-p: 1.1 (0.6-1.8) s-p: 0.3 (0.1-0.5)** s-r: 0.3 (0.2-0.5)**
Soldiers called up for recruitment should go through a psychiatric genetic test	39	42	24	r-p: 1.1 (0.8-1.6) s-p: 0.5 (0.3-0.8)** s-r: 0.5 (0.3-0.8)**
Persons occupying highly responsible jobs (e.g., pilots) should go through a psychiatric genetic test	46	57	27	r-p: 1.6 (1.1-2.3)* s-p: 0.4 (0.3-0.7)** s-r: 0.3 (0.2-0.5)**
Persons wanting to adopt a child should be able to show a psychiatric genetic certificate	21	31	12	r-p: 1.7 (1.2-2.6)** s-p: 0.5 (0.3-1.0) s-r: 0.3 (0.1-0.6)**
Persons wanting to adopt should be allowed to demand a psychiatric genetic certificate of the child	20	23	6	r-p: 1.2 (0.8-1.9) s-p: 0.3 (0.1-0.6)** s-r: 0.2 (0.1-0.6)**

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$ .

TABLE IV. Intentions Toward Testing (Agree in %)

Statement	Patients (n = 397)	Relatives (n = 164)	Students (n = 100)	Total (n = 661)
I would have a psychiatric genetic test				
-only if effective treatment/prevention exists	45	52	58	48
-notwithstanding treatment possibilities	38	23	22	32
Total	83	75	80	80
I would have my own child tested				
-only if effective treatment/prevention exists	41	53	56	46
-notwithstanding treatment possibilities	30	20	16	26
Total	71	73	72	72

treatment possibilities. Significantly more students than patients would test only if treatment/prevention existed (OR = 1.7,  $P = 0.021$ ).

The overall intention to test one's own child did not differ between groups, but patients were significantly more interested in testing notwithstanding treatment possibilities than both students (OR = 2.3,  $P = 0.007$ ) and relatives (OR = 1.7,  $P = 0.019$ ).

We asked the same questions regarding genetic testing for somatic illness. Respondents (78.3%) would take a genetic test for a serious somatic disease, 24.0% would test notwithstanding treatment possibilities, 54.3% only if treatment/prevention was an option. No significant differences between the proportions of participants wanting psychiatric and somatic genetic testing appeared.

### Reproductive Choices (Tables V–VII)

In Table V 36.6% of the respondents were against prenatal testing for psychiatric diseases. As more patients and relatives than students answered “don't know” to this question, the actual proportion of participants stating not to be against psychiatric prenatal testing was 44.6% of the relatives, 50.3% of the patients, and 63.5% of the students; students being significantly more supportive than both patients (OR = 1.7,  $P = 0.02$ ) and relatives (OR = 2.2,  $P = 0.004$ ). Of these 27.1% were against prenatal testing for somatic diseases, significantly fewer students expressing this attitude. There were significantly less support for prenatal testing for psychiatric diseases than for somatic diseases among both patients (OR = 1.5,  $P = 0.006$ ) and students (OR = 2.5,  $P = 0.01$ ). Significantly more students than patients and relatives expected psychiatric genetic testing to lead to more abortions.

To measure respondents' attitudes concerning reproduction, we constructed two scenarios for genetic testing, added different risk estimates and asked the participants to imagine

if, given the circumstances of the scenario, they would (1) avoid having children, (2) have an abortion.

Scenario 1: Imagine you had a genetic test and the result showed a certain risk of your future child/expected child having a severe mental illness, which could not be controlled with medicine, would jeopardize the ability to take care of a family, would include a risk of suicide and result in disability retirement at the age of 45. Would you then avoid having children/have an abortion? (results shown in Table VI).

Scenario 2: Imagine you had a genetic test and the result showed a certain risk of your future child having a moderate mental illness, including 2–3 episodes of illness and 1–2 hospitalizations, but medical treatment would make him/her able to live a close to normal life. Would you then avoid having children/have an abortion? (results shown in Table VII).

Relatives expressed significantly higher intention than patients to avoid having children/have an abortion in seven out of eight situations and in five out of eight situations compared to students. Both the change of scenario and the change of risk estimates resulted in significant changes in intentions in all groups. The scenarios evoked the highest numbers of “don't know” in the questionnaire (13–22%).

## DISCUSSION

### Access to Testing and Information

At first, the results on attitudes toward access to genetic testing and information reveal a high level of agreement among respondents regarding privacy and voluntariness of gene tests. A large majority of the respondents support the general statements of the right to know and not to know about their hereditary characters and the right to keep genetic data confidential. The large majority opposes that members of families with psychiatric diseases should be obliged to test for the disease; and the support for employers' and insurance

TABLE V. Attitudes Toward Prenatal Testing (Agree in %)

Statement	Patients (p) (n = 397)	Relatives (r) (n = 164)	Students (s) (n = 100)	OR (95% CI)
I am generally against the possibility of parents knowing of their unborn child's disposition for psychiatric disease	37	41	29	r-p: 1.2 (0.8–1.8) s-p: 0.7 (0.4–1.2) s-r: 0.6 (0.4–1.0)
I am generally against the possibility of parents knowing of their unborn child's disposition for somatic disease	27	34	14	r-p: 1.4 (0.9–2.1) s-p: 0.4 (0.2–0.8)** s-r: 0.3 (0.2–0.1)**
The access to psychiatric genetic testing will lead to more abortions	69	66	86	r-p: 0.9 (0.7–1.3) s-p: 2.9 (1.5–5.3)** s-r: 3.2 (1.6–6.3)**

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$ .

TABLE VI. Attitudes Toward Reproduction (Agree in %)

Risk estimate	Statement	Patients (p) (n = 397)	Relatives (r) (n = 164)	Students (s) (n = 100)	OR (95% CI)
25% risk	Avoid having children	41	59	44	r-p: 2.1 (1.4-3.1)*** s-p: 1.1 (0.7-1.8) s-r: 0.6 (0.3-0.9)*
75% risk	Avoid having children	73	81	87	r-p: 1.5 (1.0-2.5) s-p: 2.4 (1.3-4.7)** s-r: 1.6 (0.8-3.3)
25 % risk	Have an abortion	38	53	41	r-p: 1.9 (1.3-2.7)** s-p: 1.1 (0.7-1.8) s-r: 0.6 (0.4-1.0)
75 % risk	Have an abortion	64	74	81	r-p: 1.6 (1.0-2.3)* s-p: 2.4 (1.4-4.1)** s-r: 1.5 (0.8-2.8)

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$ .

companies' access to genetic knowledge is almost non-existent. Genetic testing so far is pictured as a personal choice. Jallinoja [2002] found similar attitudes toward genetic testing in general in a Finnish population and interpreted these findings to be in accordance with current mainstream bioethics, describing autonomy, privacy, equality, and justice as the prime values to be guiding healthcare. The ethical dilemmas raised by genetics have primarily been met by bioethical principles. Whereas American bio ethicists Beauchamp and Childress [1979] described four principles central to biomedical ethics: respect for autonomy, non-maleficence, beneficence, and justice, these principles were later rewritten in a European context to include respect for autonomy, dignity, integrity, and vulnerability [Rendtorff and Kemp, 2000]. The Nuffield Council on Bioethics [1998] focused on two central principles: limiting harm and suffering to humans and maintaining respect for human beings and human dignity. Despite variation, the focus of bioethical principles has mainly been on the individual [Hodge, 2004]. Privacy and confidentiality have been promoted as the key ethical concerns in genetic testing, in recognition of the possible dangers of genetic discrimination when it comes to health care, insurance, and employment [Bhardwaj, 2006]. But in practice, given the characteristic of genetic knowledge involving not only one individual but also a group of related individuals, these principles are challenged by opposing the right to know and the right not to know—and by posing the question of balancing the autonomy of a person with the utilitarian perspective that disclosure could protect a large number of people [Bhardwaj, 2006].

These contradictions and dilemmas seem to show in public opinion, too. While a large number of respondents agree that everybody has the right to know about their genes, at the same time an even larger number agree that everybody has the right to decide that they do not want to know about their risk genes, and the right to keep genetic data confidential. These attitudes may well mirror mainstream bioethics of privacy and autonomy, but they also mirror some of the ethical dilemmas of this field. Given that the actual possibility of testing an individual may depend on testing affected relatives to identify possible risk genes, the above stated right of knowing and not knowing may clash in the ethical dilemma of the right to know versus the right not to know [Chadwick et al., 1997]. And the widespread attitude of not harming the privacy of the tested individual by informing close relatives about test results without the permission of the tested person do contradict both the relatives' right of knowing and the physician's obligation to limit harm and suffering.

Whereas general attitudes (Table II) may express values in accordance with mainstream bioethical principles of autonomy and privacy, there is more variation in attitudes when asked about concrete situations (Table III). Patients and relatives seem generally less protective of autonomy and privacy when asked about testing in specific situation. A considerable proportion of patients and relatives support general statements of autonomy, privacy, and confidentiality, and at the same time agree that testing could be demanded of soldiers, pilots, and couples wanting to adopt, thereby illustrating that contradictory attitudes in this field are not rare. Jallinoja's Finnish sample showed the same tendencies, with

TABLE VII. Attitudes Toward Reproduction (Agree in %)

Risk estimate	Statement	Patients (p) (n = 397)	Relatives (r) (n = 164)	Students (s) (n = 100)	OR (95% CI)
25 % risk	Avoid having children	21	30	11	r-p: 1.7 (1.1-2.6)* s-p: 0.5 (0.2-0.9)* s-r: 0.3 (0.1-0.6)**
75% risk	Avoid having children	30	41	23	r-p: 1.6 (1.1-2.4)* s-p: 0.7 (0.4-1.2) s-r: 0.4 (0.3-0.8)**
25 % risk	Have an abortion	13	21	8	r-p: 1.8 (1.1-3.0)* s-p: 0.6 (0.3-1.3) s-r: 0.3 (0.2-0.8)**
75 % risk	Have an abortion	24	37	23	r-p: 1.8 (1.2-2.7)** s-p: 0.9 (0.5-1.5) s-r: 0.5 (0.3-0.9)*

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$ .

a considerable proportion of the respondents contradicting their general attitudes when asked more specific questions [Jallinoja et al., 1998]. Contradictory attitudes and ambivalence toward new medical technology in general and toward genetics in specific has been reported in several studies, and the suggested explanations for this phenomenon range from lack of knowledge to the stance that technologies involving moral questions will always raise ambivalent attitudes [Jallinoja et al., 1998]. In our sample, students seem to express more consistent attitudes, sticking to the principles of protecting the individual's right to privacy and confidentiality and not supporting any kind of forced testing. We cannot decide if this relates to them being more knowledgeable in relation to genetics or being less experienced in relation to mental disease or relate to other factors. Even though the patients and relatives are significantly more supportive of forced psychiatric genetic testing in specific situations, this is not enough to say that they are less concerned with the possible dangers. Their motives for supporting these practices may differ from the students', and a fully understanding of the expectations toward psychiatric genetics would be enhanced by investigating these different motives.

Support for availability of psychiatric genetic testing for whoever wants it is relatively high but significantly higher when it comes to the target group of psychiatric genetic testing. Students especially differentiate between the availability of testing for everybody and the more specific use of it. According to a Finnish survey measuring attitudes of health care professionals toward genetic screening and testing, health care professionals were likewise more inclined toward selective genetic testing for schizophrenia than for screening [Toiviainen et al., 2003]. This differentiation may be related to more knowledge of genetics and hence more realistic expectations toward the benefits of genetic testing. However, as Toiviainen puts it, it is not necessarily solely a question about knowledge but a difference between the perspectives of health care professionals' and lay peoples' attitudes: the first expressing professional opinion, the latter expressing personal thoughts.

### Intentions Toward Genetic Testing

A large majority of the participants in our study express an intention to test, thereby resembling samples questioned in other studies. The exact wording of questions differs in these studies, some of them asking if genetic testing for psychiatric illness should be available, others if the participants themselves intend to test. All in all, 75–99% of respondents in these studies express positive attitudes toward psychiatric genetic testing, indicating a highly positive attitude to psychiatric genetics among persons suffering from bipolar disorder or schizophrenia [Smith et al., 1996; Trippitelli et al., 1998; Jones et al., 2002; Delisi and Bertisch, 2006] and patients suffering from a broad range of mental diseases [Illes et al., 2001]. Studies measuring attitudes toward testing of children also found patients to be highly supportive of this, proportions of supporters ranging from 77–89% [Smith et al., 1996; Trippitelli et al., 1998; Jones et al., 2002]. All the cited studies including our own recruited psychiatric patients from genetic projects and these patients may be more positive toward psychiatric genetics than other patients. However, Jones et al. included both patients involved and not involved in genetic research, and found no differences in attitudes, suggesting that these views may be representative of sufferers more generally [Jones et al., 2002].

The difference between patients and relatives regarding the intention to test may not surprise, since relatives in this sample mainly consist of parents, most of them not suffering from mental illness and not in an age where childbearing is an

issue. In fact, the relatively high numbers of relatives wanting to test is more surprising, raising the question of what they expect to gain from testing.

The relatively large amount of the sample, especially among the group of patients, expressing an intention to test notwithstanding treatment possibilities, indicates that testing is not just perceived as a way to better treatment. Smith et al. [1996] similarly found a high level of interest in psychiatric genetic testing even without preventive treatment options. The reasons for wanting psychiatric genetic testing without better treatment options should be explored to investigate the motives and expectations possible future users of psychiatric genetic counseling may have regarding testing. To provide relevant information about genetics, it is necessary to know the expectations toward testing, and whether these expectations are in balance with what genetics realistically can offer or may be too optimistic, mainly reflecting the hopes of the respondents.

### Reproductive Choices

Although we did not ask specifically if participants intended to use psychiatric prenatal testing, we asked about general attitudes toward this possibility and found half of the participants supporting this. Other studies asking directly about participants' intentions to use psychiatric genetic prenatal testing found varying proportions expressing this intention. Trippitelli et al. [1998] reported 43.9% of 41 bipolar patients and their spouses wanting to test a fetus, Jones et al. [2002] found 29% of 147 bipolar patients wanting prenatal testing for bipolar disorder, and Delisi and Bertisch [2006] found 56.2% of 48 members of families with schizophrenia wanting prenatal testing. What is similar across studies, including ours, is a weaker support for prenatal testing than for testing of children or self. Furthermore, whereas we found no significant differences between the proportions of participants wanting psychiatric and somatic testing themselves, both patients and students in our sample show significantly less support for prenatal testing for psychiatric illness than for somatic illness. Smith et al. report similar results, measuring the intentions of bipolar patients, medical students, and psychiatric residents in relation to termination of a pregnancy in the case of a positive test result. A higher proportion of the total sample would terminate pregnancy for a severe or life-threatening disorder than for bipolar disorder. Smith explains this difference with the fact that somatic illness may be perceived as potentially more fatal than bipolar disease [Smith et al., 1996], and this interpretation may be part of the explanation regarding our results too. Additionally, the weaker support for psychiatric prenatal testing than for other types of testing may point to the more controversial nature of this question.

Yet, a substantial part of the participants, especially students, agrees that psychiatric genetics will lead to more abortions, and a substantial part of the total sample reports a hypothetical intention to avoid having children/have an abortion in case of risk for severe mental illness. Numbers indicate that some of the respondents stating to be against prenatal testing express hypothetical intention to have an abortion in some of the situations given the option of risk estimation.

Significantly more relatives, most of them being parents to one or more children suffering from mental illness, state that they would avoid having children or have an abortion, given the circumstances described in the scenarios. Patients themselves are significantly less inclined to avoid having children or have an abortion. These results may be comparable to results reported from other studies, relating the patients' tendency to minimize the burden of their mental illness compared to both spouses [Targum et al., 1981; Jones et al., 2002] and parents

[Schulz et al., 1982] to their more positive intentions toward reproduction.

Both change in described severity of illness and change in risk estimate significantly influenced stated intentions to avoid having children or terminate a pregnancy. These results are similar to results from a study assessing the intentions toward termination of pregnancy among members of a bipolar support group (mainly patients), medical students, and psychiatry residents. This study found the hypothetical decision to terminate a pregnancy to be mediated by the anticipated course of the illness. Besides, psychiatry residents had the highest intention to terminate a pregnancy for all clinical scenarios depicting various courses of illness [Smith et al., 1996]. We found this difference between students and patients in the cases of severe mental illness and high-risk estimates, students reporting higher hypothetical intention to avoid having children/terminate a pregnancy.

The questions regarding prenatal testing and reproduction revealed significant differences between the groups and high numbers of "don't know". Though the scenarios ask about personal intentions, the answers might reflect different approaches to the question. We cannot tell which variables explain the differences, but the results highlight the fact that a future psychiatric genetic counseling will be the meeting point of these different perceptions and approaches regarding reproduction, and that decision-making in this situation will be complex. The possibility of future counselors' and counselees' differing views on reproductive decisions should be an issue in the education of psychiatric genetic counselors aiming at non-directive genetic counseling.

### Somatic Versus Psychiatric Genetic Testing

Attitudes toward psychiatric genetic testing seem to be as positive as attitudes toward somatic genetic testing, as we did not find any significant differences between the proportions of participants opposing psychiatric and somatic genetic testing and between the proportions of participants intending to test for psychiatric and somatic disease. Somatic illness is, of course, a crude category, but we wanted to assess if the perceived dichotomy between somatic and psychiatric illness concerning attribution and stigma would show in attitudes toward genetics. Studies investigating attitudes toward somatic genetics among target populations have found varying but mainly high numbers of respondents supporting genetic research and testing [Lerman et al., 1995; Lafayette et al., 1999]. We found no other studies comparing attitudes toward psychiatric and somatic genetic testing. Since psychiatric genetic testing has been pictured as potentially more problematic than somatic genetic testing because of the history of eugenics and the issues of stigma and discrimination, we would have expected differences in attitudes. These differences show in relation to prenatal testing only, prenatal psychiatric genetic testing receiving significantly less support than prenatal somatic genetic testing. Whether these differences pertain to the different perceptions of the illnesses being fatal or reflect the more controversial nature of this question cannot be concluded from this study but deserves further investigation.

While hypothetic interest in genetic testing for other than psychiatric diseases has been shown to be a poor predictor of actual test uptake [Lerman et al., 2002], the high numbers of participants expressing intention to test may not mirror the actual future demand for psychiatric genetic testing. The results may be more indicative of the general accept of psychiatric genetic research and testing than of future uptake. As a measure of accept, the results showing same degree of support for psychiatric and somatic genetic testing is an important finding in relation to the debate on mental illness and genetics.

### Implications for Further Research and Future Practice

Assessing the opinions of the public toward new medical technologies has been widely recognized as providing valuable knowledge for the public debate and for policymaking. In addition, scholars have argued that knowledge of attitudes toward genetics among specific affected subgroups is needed to understand the special concerns and preconceptions of these individuals [Gollust et al., 2005]. In developing educational programs concerning genetic innovations in medicine, policymakers will have to take into account pre-existing lay knowledge, views, and expectations of different groups of citizens toward these developments. This knowledge will also enhance the clinical validity of both present and future psychiatric genetic counseling [Austin and Honer, 2005].

Results from this survey represent the attitudes toward psychiatric genetics among a large group of patients with different psychiatric diagnoses and their relatives. Our sample of patients and relatives represents a very well described target group in relation to psychiatric genetics, and their attitudes, expectations, and expressed intentions are relevant to the public debate and future policymaking concerning psychiatric genetics as well as to the planning of a psychiatric genetic counseling service. Furthermore, the attitudes of medical and psychology students and especially the differences in attitudes between these possible future providers and consumers of psychiatric genetic testing and counseling should be taken into account when results from psychiatric genetic research are to be integrated into practice and in the education of future psychiatric genetic counselors. The education of health professionals in genetics should include personal, social, ethical, religious, and political issues [Jallinoja et al., 1998], and it is therefore important to be aware of possible differences in attitudes between future users and providers of psychiatric genetic counseling. In addition, the contradictory attitudes toward genetics found in several surveys may result in uncertainty and even anxiety in decision-making situations [Jallinoja et al., 1998]. Future psychiatric genetic counselors will face the contradictory feelings of their patients and coping with these feelings will be part of the counseling process.

We cannot conclude from this study if knowledge of genetics has an influence on attitudes and intentions regarding psychiatric genetics, but the results do reveal a wish for more knowledge expressed by all participating groups. Especially the patients and relatives report low knowledge on genetic testing and a perception of the mass media bringing too little information on psychiatric genetics in general. As the obligation to inform about psychiatric genetics does not rest on the media, this need should be recognized by the scientific society and the public health system as well.

The limitations of our study are, however, evident as well. Although the sample for the initial genetic studies were recruited through a diversity of sources: the psychiatric hospital, psychiatrists, and advertisements in newspapers and on the Internet, all patients participating did initially volunteer for genetic projects, rendering it possible that the sample may be more homogeneous and more in favor of psychiatric genetics than other psychiatric patients. As our results on general attitude toward psychiatric genetics are very similar to results from another study, including patients not involved in psychiatric genetic research, they may represent the attitudes of sufferers more generally, but this should be further investigated in samples including patients not involved in genetic research. Also, in our study we included all patients in one category of patients, and their relatives in one category of relatives. As different diseases involve different levels of severity and stigma, it is likely that attitudes may differ depending on diagnosis. Our groups were

too small to analyze associations between diagnosis and attitudes, but possible differences in attitudes depending on diagnosis should certainly be investigated in a larger sample of both patients and relatives.

While medical and psychology students are not yet health care providers, they will be in the future, which includes psychiatric genetic testing and counseling. Our results cannot represent the views of healthcare providers involved in psychiatric genetics, since the knowledge and attitudes of professionals trained in psychiatry or genetics (or both) may differ from students' knowledge and attitudes. Still, results do provide knowledge of the attitudes of those who will be the ones to integrate the new psychiatric genetic knowledge into practice, and the ones who may be recruits for psychiatric genetic counseling education.

We are aware that differences in attitudes between students and patients/relatives in our sample may relate to various factors and that a survey has some intrinsic limitations in this regard. Participants can only answer the questions posed and do neither have the opportunity to express which further issues they consider important nor the reasoning behind their answers. We did test the questionnaire in students and revised it based on their feedback, but testing it in patients too may have added further issues. Since the field of psychiatric genetics is relatively new we chose a combination of the survey method with more exploratory methods. The questionnaire was based on literature on bioethics and on the results from a focus group study including patients, and we are now conducting additionally focus groups with some of the participants from the study to explore their perception of psychiatric genetics and further its implications.

Obviously, questions raising the same response among almost all respondents are not very informative of differences. In our survey, some of the general questions failed to differentiate between participants, whereas questions describing a specific practice or scenario revealed both in-group contradictions and differences between groups. Other studies concerning the uptake of genetic testing have reported that actual uptake rates are typically much lower than indicated by intentions measured before testing is available [Lerman et al., 2002]. This may illustrate that the value of asking very general questions in this area is limited and that surveys asking more specific questions, or even interview studies, are relevant. General questions conveying health enhancing values or principles supporting the autonomy and privacy of the individual may be difficult not to agree with, but they may not be very predictive of actual behavior. More specific questions describing situations and scenarios reveal more relevant information of use to further research into the preconceptions and motives of future psychiatric genetic counselees and to the application of results from psychiatric genetic research into practice.

Some of the questions posed may picture possibilities that will never be reality. Furthermore, participants may not be very knowledgeable about genetics and their expectations may be overstated, mainly expressing their hopes. But this was exactly what we intended to measure. The expectation that major genes will be found is still present in the mass media and therefore presumably among the public. We did not pose the questions in order to decide how things should be, but rather to explore the prevailing attitudes and preconceptions regarding psychiatric genetics among those who may seek information about psychiatric genetics and may be future users and providers of a psychiatric genetic counseling service.

We are aware of the relevant philosophical question whether normative information can be drawn from descriptive data, but without addressing this extensive discussion

further we would like to emphasize that we never intended to draw ethics from a survey. Our intention was to measure the attitudes toward psychiatric genetic testing among members of the future target group and to relate these results both to future practice and to the wider ethical debate.

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