

Potential Consumers' Attitudes Toward Psychiatric Genetic Research and Testing and Factors Influencing Their Intentions to Test

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Psychiatric genetic research brings on the possibility of psychiatric genetic testing. The optimal and responsible utilization of genetic testing depends on knowledge of the potential consumers' attitudes and expectations regarding testing. The aim of this study was to assess potential consumers' attitudes and expectations toward psychiatric genetics and factors influencing their intentions to test. A questionnaire constructed to assess attitudes and intentions toward psychiatric genetic testing was mailed or given in person to individuals participating in different genetic studies aiming at identifying genes predisposing for mental illness. A total of 397 persons diagnosed with major depression, bipolar disorder, schizophrenia, or anxiety disorder participated in the survey. A large majority of the sample expressed an intention for themselves and their children to participate in psychiatric genetic testing. Support for prenatal testing was considerably less strong. A large minority expressed intention to test regardless of treatment possibilities. Intentions to test were positively associated with being a parent, trust in researchers, and expecting to feel better prepared for fighting the disorder when knowing of the presence of risk genes. Intentions were negatively associated with the fear of psychiatric genetic research bringing on too many difficult choices and fearing not to be able to cope with the results of a psychiatric genetic test. These results indicate that psychiatric genetic testing is not just perceived as a way to better treatment. Other expectations may motivate testing even though the clinical validity of the test is poor.

Introduction

PSYCHIATRIC GENETICS RAISES ethical, legal, social, and psychological issues (Nuffield Council on Bioethics, 1998). Whereas Nuffield Council on Bioethics took a rather conservative stance, discouraging testing on the basis of the poor clinical validity and the risk of negative side effects, geneticists have anticipated that psychiatric genetic research will lead to the development of presymptomatic and prenatal tests (Jones *et al.*, 2002). Recently, a small California company was the first to market a test in psychiatric genetics, and other companies plan on offering similar direct-to-consumer psychiatric genetic testing via the Internet within a few years (Couzin, 2008).

Great hopes have been attached to psychiatric genetics, both regarding the goal of better treatment and prevention (Craddock and Jones, 2001; Insel and Collins, 2003) and the anticipated de-stigmatizing effect of attributing mental illness to biological causes (Phelan, 2002). At the same time, critics have warned that psychiatric genetics will lead to a new eugenics (Rose, 1998), increasing stigma and discrimination of

the mentally ill, even creating new mechanisms of discrimination (Chadwick, 2000; Phelan, 2005).

While psychiatric genetic knowledge is increasing, little is known about the significance of this knowledge to the ones it concerns. In a recent study a sample of psychiatrists were consistently positive toward psychiatric genetic testing but stressed the role of patient safeguards such as genetic counseling (Hoop *et al.*, 2008). A previous survey of 352 psychiatrists' knowledge of and opinions on genetics revealed that the respondents viewed genetic information as clinically relevant, but that they did not feel prepared or competent to integrate genetic knowledge into practice (Finn *et al.*, 2005), and a pilot study among genetic counselors indicated a substantial need for information about psychosocial issues involved in psychiatric genetic counseling (Peay and McInerney, 2002). To enhance the effect of both the ongoing psycho-educative efforts and a future counseling service offered to individuals and families with mental disorders, we need knowledge of these individuals' attitudes, expectations, preconceptions, and intentions regarding psychiatric genetic research and testing (Hodge, 2004; Gollust *et al.*, 2005).

Few studies have examined the attitudes toward psychiatric genetics among persons suffering from mental illness (Smith *et al.*, 1996; Trippitelli *et al.*, 1998; Illes *et al.*, 2002a; Jones *et al.*, 2002; Meiser *et al.*, 2005; Delisi and Bertisch, 2006). To our knowledge, no studies have examined if persons with different diagnoses have different attitudes and expectations toward psychiatric genetics, or which other variables may have an influence on intentions toward psychiatric genetic testing.

We therefore set the aim of assessing the attitudes toward psychiatric genetic research and testing among persons with different psychiatric diagnoses, and to examine which factors are related to intentions to test, to better understand the expectations toward testing and the perceived benefits and barriers to test uptake.

Materials and Methods

We conducted a survey assessing attitudes, expectations, and preconceptions concerning psychiatric genetic research and testing among persons diagnosed with different psychiatric diseases, their relatives, and medical and psychology students. Results from this survey concerning attitudes toward access to genetic testing and genetic information, and concerning differences in attitudes between the surveyed groups are reported elsewhere (Laegsgaard and Mors, 2008). This paper reports the attitudes of the persons suffering from mental disease, the differences between groups of persons suffering from different mental diseases, and the expectations and attitudes toward psychiatric genetic testing associated with intention to test.

Participants

The participants volunteered 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 (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 (Kristensen *et al.*, 2007).
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.

The questionnaire was administered in person to the participants who were still participating in the genetic studies, and mailed to the participants previously participating in these studies. A total of 452 persons received the questionnaire. Of these, 397 persons responded, giving a response rate of 88%. In 248 of these participants, a diagnosis of a mental illness was confirmed, using the semistructured diagnostic interview SCAN 2.1 (WHO, 1998). Diagnoses included recurrent depression ($n = 79$); bipolar disorder ($n = 29$); schizophrenia ($n = 35$); and panic disorder, social phobia, and agoraphobia ($n = 105$). Besides, 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 persons diagnosed with depression.

The survey instrument

A questionnaire was developed specifically for this study on the background of (1) literature concerning ethical, social, legal, and psychological issues raised by genetics, with special attention to issues relevant to psychiatric genetics (Nuffield Council on Bioethics, 1998); (2) existing research on attitudes toward psychiatric genetic research and testing (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, all diagnosed with depression and interviewed on two occasions. The questionnaire was reviewed by a psychologist and an anthropologist, both experienced in the survey method, and it was revised to its final version, containing items measuring knowledge of mental illness and genetics and attitudes and intentions toward psychiatric genetic research and testing.

Items measuring knowledge of mental illness and genetics were presented as statements, for example, "Even if you are completely well, you can have genes predisposing for mental illness" and with the possibility of answering "yes," "no," or "do not know." One item measuring perception of mental illness etiology was presented as the statement, "Mental illness can have genetic causes," and with the possibility of answering "yes," "no," or "do not know." One item measuring level of religiousness was presented as a question, "How important is your religion to you?" and with five answering possibilities ranging from "utmost important" to "not important at all."

Items measuring attitudes were presented as statements, for example, "I fear psychiatric genetic research bringing on an attitude of some lives being worth more than others." Items measuring intentions to test for genes predisposing to mental illness were assessed in two questions: (1) I would have a genetic test aiming at estimating my risk of developing a mental illness (or having a relapse), regardless of treatment possibilities and (2) I would only test for a mental illness if the illness could be treated or prevented effectively. Five answering possibilities were given to the statements assessing attitudes and intentions: "Completely agree," "mainly agree," "mainly disagree," "completely disagree," and "do not know."

The last section of the questionnaire contained items measuring sociodemographic variables. A short description of psychiatric genetic research, its possible prospects and implications, risk genes, and psychiatric genetic testing was given at the beginning of the questionnaire. Respondents were asked, when answering the questions, to imagine that genetic testing was possible.

Statistical analysis

Data analysis was conducted in five steps:

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

Second, a knowledge scale of seven questions probing the respondents' knowledge of genetics and mental illness was analyzed using item-response theory. DIGRAM was used to validate the knowledge scale (<http://www.biostat.ku.dk/~skm/skm/index.html>). This program tests if measurement data fit a Rasch model, and is a way of evaluating how close data are to perfect measurement (Fischer and Molenaar, 1995). The analysis resulted in a scale of seven items. A test of

global homogeneity (conditional likelihood ratio = 10.0; $df = 6$; $p = 0.124$) indicated that the scale fitted a Rasch model. The requirements of unidimensionality, monotonicity, and no local dependence (LD) were met. When controlling for multiple testing, there was no differential item function (DIF) with either age (conditional likelihood ratio = 35.3; $df = 24$; $p = 0.064$) or gender (conditional likelihood ratio = 13.8; $df = 6$; $p = 0.032$). The Cronbach α coefficient (0.49) indicated fairly poor reliability, which may be a consequence of using relatively few items to measure a complex variable such as knowledge. The scale was treated as an interval scale with values from 0 to 7. *T*-tests were used to compare group scores.

Third, the answers of the four diagnostic groups on questions of attitudes and intentions were calculated and compared using odds ratios (OR). When analyzing the answers to statements concerning attitudes, the proportions of participants answering "completely agree" or "mainly agree" were combined and reported in percentage of total answers (including "mainly disagree," "completely disagree," and "do not know").

Fourth, the two items assessing intention to test were combined, separating respondents into four groups: group 1, including participants choosing the "do not know" option in both items; group 2, including participants stating that they would not test in both items; group 3, including the partici-

pants stating that they would only test if the mental illness could be treated or prevented effectively; and group 4, stating that they would test regardless of treatment possibilities.

Fifth, multiple logistic regression models were used to test the association of sociodemographic and attitude variables to respondents' intentions toward taking a psychiatric genetic test. We created a model testing the association of the following variables to intention to test: diagnose, age, gender, educational level, and being a parent. These variables were all entered in one basic model, and the results were presented as the association of each variable to intention to test, controlling for the other variables. We kept this model for further analysis to adjust for these background variables when testing the association of the variables of knowledge, religiousness, attitudes, and expectations to intention to test. Each of these variables was added separately to the model. When entering the variables of attitudes and expectations into the model, respondents answering "do not know" to the specific question were excluded. This was done to avoid the findings of significant associations between attitudes and intentions, which were in reality associations between answering "do not know" to questions on attitudes and questions of intentions. A likelihood ratio test was applied to test if the variable in question improved the model significantly, and the variables improving the model the most were added using stepwise forward

TABLE 1. SAMPLE CHARACTERISTICS

Characteristics	Patients with anxiety disorders (n = 105)	Patients with bipolar disorder (n = 29)	Patients with schizophrenia (n = 35)	Patients with depression (n = 228)
Age groups (%)				
1 (18–29 years)	41.0	65.5	34.3	4.4
2 (30–39 years)	23.8	20.7	37.1	20.4
3 (40–49 years)	18.1	10.3	11.4	27.1
4 (50–59 years)	14.3	3.5	11.4	27.1
5 (≥ 60 years)	2.7	0	5.7	20.9
Gender (%)				
Male	25.7	51.7	48.6	25.9
Female	74.3	48.3	51.4	74.1
Have one or more children (%)	43.8	7.1	48.6	78.2
Educational level (%)				
<13 years	56.4	63.0	41.2	30.5
13–16 years	33.7	33.3	41.2	57.5
>16 years	9.9	3.7	17.7	12.0
Religious background (%)				
Protestant	62.8	40.7	57.1	71.8
Other	5.8	22.3	14.3	9.1
Not religious	31.4	37.0	28.6	19.1
Importance of religion (%)				
Most/very important	9.3	22.2	29.4	19.6
Moderately important	26.7	18.5	26.5	38.6
Not very important/not important at all	64.0	59.3	44.2	41.8
Knowledge score				
Mean (SD)	4.9 (1.4)	4.1 (1.9)	4.9 (1.3)	4.1 (1.5)
Treatment of mental illness (%)				
Have been hospitalized	14.3	79.3	85.7	36.4
Have received medical treatment	48.6	93.1	94.3	92.1
Have received psychotherapeutic treatment	67.6	62.1	65.7	63.2
Perception of mental illness (agree in %)				
Mental illness can have genetic causes	71.1	57.1	93.8	89.8
I think the mental illness in my family is hereditary	60.0	48.3	71.4	78.5

inclusion with a significance level of 0.05 until no improvement of the model was attained.

This procedure was used both to identify variables associated with intention to test if effective treatment or prevention exist (analysis 1), and variables related to intention to test regardless of treatment possibilities (analysis 2). The statistical package STATA 9.1 was used for statistical analysis (<http://www.stata.com/>).

Results

Sample characteristics

The background variables of the study sample are presented in Table 1.

Knowledge of mental illness and genetics

T-tests comparing the diagnostic groups' scores on the knowledge scale showed that persons with anxiety disorders had a higher score than persons with depression ($t=4.4$; $p<0.001$) and bipolar disorder ($t=2.5$; $p=0.013$) and that persons with schizophrenia had a higher score than persons with depression ($t=3.1$; $p=0.002$) and bipolar disorder ($t=2.1$; $p=0.041$). When asked, only 13% of all respondents

thought they had sufficient knowledge of psychiatric genetics. Eighty-four percent of respondents agreed that there is too little information about psychiatric genetics in the mass media.

Attitudes and expectations toward psychiatric genetic research and testing

Table 2 presents the participants' answers to statements concerning attitudes and expectations toward psychiatric genetic research and testing. The table presents the proportions (%) in each of the four patient groups answering "completely agree" or "mainly agree" to the statement and the significance level of differences between groups.

A large majority of the total sample expressed positive attitudes toward psychiatric genetic research (92%, not shown in table) and trusted that the researchers in psychiatric genetics act for the best of mankind (84%), yet large minorities expressed concern that psychiatric genetic research will bring on too many difficult choices (39%), an attitude of some lives being worth more than others (38%), and discrimination of at risk individuals (50%). These attitudes did not differ between the groups. Seventy percent of all the participants expected that spreading the knowledge that mental disorders are partly

TABLE 2. ATTITUDES AND EXPECTATIONS TOWARD PSYCHIATRIC GENETIC RESEARCH AND TESTING (AGREE IN %)

Statement	(1) Patients with anxiety disorders (n = 105)	(2) Patients with bipolar disorder (n = 29)	(3) Patients with schizophrenia (n = 35)	(4) Patients with depression (n = 228)	Significant differences
I trust that the researchers in psychiatric genetics act for the best of mankind	81	89	77	86	
I fear psychiatric genetic research bringing on too many difficult choices	43	35	34	38	
I fear psychiatric genetic research bringing on an attitude of some lives being worth more than others	37	34	43	39	
I fear psychiatric genetic research bringing on discrimination of at risk individuals concerning work, insurance, etc.	49	45	57	50	
Spreading the knowledge that mental disorders are partly genetic will make it less shameful to suffer from a mental disease	66	52	69	75	(2)–(4) ^a
I would feel less guilty concerning my child's mental disease if I knew it was primarily genetic determined	43	35	50	47	
I fear not being able to cope emotionally with the results of a psychiatric genetic test	45	21	43	23	(1)–(2) ^a (1)–(4) ^b (1)–(4) ^b
I fear that knowing about own risk genes could bring on the mental disorder in question	53	36	35	30	(3)–(4) ^a
I would feel more prepared for fighting the disorder, knowing of the presence of risk genes	54	59	62	59	

^a $p < 0.05$.

^b $p < 0.01$.

TABLE 3. INTENTIONS TOWARD TESTING (AGREE IN %)

Statement	Patients with anxiety disorders (n = 105)	Patients with bipolar disorder (n = 29)	Patients with schizophrenia (n = 35)	Patients with depression (n = 228)
I would have a psychiatric genetic test				
Only if effective treatment/prevention exists	35	28	46	51
Notwithstanding treatment possibilities	41	55	31	36
Total	76	83	77	87
I would have my own child tested				
Only if effective treatment/prevention exists	35	24	34	46
Notwithstanding treatment possibilities	37	31	34	26
Total	72	55	68	72

genetic would make it less shameful to suffer from a mental disease, patients with depression being significantly more hopeful on this issue than patients with bipolar disorder (OR, 2.7; $p = 0.013$). Forty-five percent of the participants would feel less guilty knowing that their child's mental disease was primarily genetic determined.

Thirty percent of the participants, significantly more patients with anxiety than patients with bipolar disorder (OR, 3.2; $p = 0.021$) and depression (OR, 2.8; $p < 0.001$), and significantly more patients with schizophrenia than patients with depression (OR, 2.5; $p = 0.013$) feared not being able to cope with the test results. Thirty-seven percent of the participants, significantly more patients with anxiety than patients with depression (OR, 2.6; $p < 0.001$), feared that knowing about their own risk genes could bring on the mental disease in question. Fifty-eight percent of all the participants expected to feel more prepared for fighting the disorder, knowing of the presence of risk genes.

Intentions toward psychiatric genetic testing

Table 3 presents the participants' answers to statements concerning intentions to test.

Eighty-three percent of the total sample expressed intention to take a psychiatric genetic test if possible; 9% did not know if they wanted to. Significantly more persons with depression than persons with anxiety expressed intention to test (OR, 2.1; $p = 0.015$). Thirty-eight percent of all the participants would test regardless of treatment possibilities. Seventy-one percent expressed intention to test their own child; 19% did not know if they would want to. Thirty percent stated that they would test their own child regardless of treatment possibilities.

We did not ask if the respondents would themselves opt for prenatal testing, but about their general attitude toward it. Thirty-seven percent of the respondents stated to be against psychiatric genetic prenatal testing; 13% did not know.

By way of comparison we asked some of the same questions regarding genetic testing for somatic illnesses. A total of 78% of the respondents would take a genetic test for a severe somatic disease, 28% regardless of treatment possibilities, and 50% only if effective treatment or prevention exists. There were no significant differences between the proportions of participants wanting psychiatric and somatic genetic testing, but significantly more respondents would want psychiatric

genetic testing regardless of treatment possibilities than somatic genetic testing regardless of treatment possibilities (OR, 1.7; $p = 0.003$).

Twenty-seven percent of the respondents were against somatic genetic prenatal testing; 9% did not know. Significantly more respondents were against prenatal testing for psychiatric than for somatic disease (OR, 1.5; $p = 0.006$).

Factors related to intention to test

Besides the background factors of diagnosis, age, gender, educational level, and being a parent, we tested all the variables presented in Table 2, level of religiousness, perception of etiology, and knowledge score in the model.

Results of analysis 1 are presented in Table 4.

Analysis 1 included participants expressing intention to test if effective treatment exists (45%) as opposed to not wanting testing (8%) or not knowing if they want testing (9%). The basic model including only background variables showed that intention to test regardless of treatment possibilities was related to diagnose, patients with depression being more interested in testing than patients with anxiety (OR, 2.3; $p = 0.025$), and to parenthood, patients having one or more children being more interested in testing than patients without children (OR, 2.7; $p = 0.006$). The difference between diagnostic groups, however, disappeared when we added variables on attitudes and expectations to the model. Being a parent stayed significantly related to intention to test. In addition, two variables, both positively related to intention to test, improved the model: expecting to feel better prepared for fighting the disorder when knowing of the presence of risk genes (likelihood ratio [LR] χ^2 , 13.5; $p = 0.0002$) and trusting in psychiatric genetic researchers (LR χ^2 , 5.6; $p = 0.0185$).

Analysis 2 included participants expressing intention to test regardless of treatment possibilities (38%) as opposed to all other participants. The model best fitted to the data included three variables besides the background variables: expecting to feel better prepared when knowing of the presence of risk genes was positively related to intention to test regardless of treatment possibilities, this variable significantly improving the model (LR χ^2 , 35.2; $p < 0.0001$). Two variables were negatively associated with intention to test regardless of treatment possibilities: fearing psychiatric genetic research to bring on too many difficult personal choices (LR χ^2 , 20.4; $p < 0.0001$) and fearing not to be able to cope with test results (LR χ^2 , 7.6; $p < 0.0058$).

TABLE 4. VARIABLES RELATED TO INTENTION TO TEST IF EFFECTIVE TREATMENT OR PREVENTION EXISTS (ANALYSIS 1)

Variable	Odds ratio	Confidence interval	p
Diagnose (reference group: anxiety disorders)			
Bipolar disorder	1.3	0.2–9.5	0.801
Schizophrenia	1.0	0.2–4.1	0.969
Depression	1.9	0.7–5.0	0.183
Gender (reference group: male)			
Female	0.7	0.3–1.7	0.385
Age (reference group: >59 years)			
40–59 years	0.4	0.1–1.3	0.119
18–39 years	1.3	0.3–4.9	0.739
Educational level (reference group: >16 years)			
13–16 years	1.4	0.3–5.8	0.783
<13 years	1.4	0.2–4.1	0.891
Parental status (reference group: no children)			
One or more children	6.2	2.2–17.1	>0.0001
I would feel more prepared for fighting the disorder, knowing of the presence of risk genes	3.7	1.6–8.5	0.002
I trust the researchers in psychiatric genetics act for the best of mankind	4.2	1.3–14.0	0.018

p-values significant on a 0.05 level are shown in boldface.

Discussion

Attitudes toward psychiatric genetic research

The highly positive attitudes toward psychiatric genetic research found in our study are similar to findings from other studies on attitudes toward psychiatric genetic research and testing (Illes *et al.*, 2002a) and toward genetic testing in general (Gaskell *et al.*, 2000). However, alongside the positive attitude is concern, as about half of those supporting genetic testing believe that certain risks are associated with this procedure (Jallinoja *et al.*, 1998; Gaskell *et al.*, 2000). Illes *et al.* (2002a) found similar results regarding psychiatric genetics as 43–60% of the sample reported ethical concerns, and the participants in our survey expressed the same complex attitudes toward psychiatric genetics. Among a large minority of the sample, the support for psychiatric genetic research coexist with fears of implications, that is, expecting psychiatric genetic research to bring on an attitude of some lives being worth more than others, and discrimination of at risk individuals. Still, hopes that psychiatric genetics will help diminish the shame associated with mental illness and the guilt concerning offspring's mental illness are widespread. These attitudes can be interpreted in the light of the discussion concerning implications of psychiatric genetics on stigma. Mental illness stigma may partly be explained by the attribution of mental illness. Persons with mental illness are more likely to be considered responsible for causing their illness (Rüsch *et al.*, 2005), thereby becoming the target of blame, shame, and guilt. Previous research suggested that biological attributions may have complex effects on mental illness stigma, reducing it along some dimensions while increasing it along others (Phelan, 2005). Expectations measured in the survey mirror these complexities, as positive and negative perceptions of the implications

of psychiatric genetics on shame, guilt, and stigma coexist. These different expectations may create both insecurity and anxiety in decision-making situations regarding testing (Jallinoja *et al.*, 1998), and future psychiatric genetic counselors need to be aware of the mixed expectations future counselees will bring to the counseling session.

Differences between diagnostic groups

Few differences in attitudes between diagnostic groups were found. Whereas these differences relate to the different diseases affecting persons differently, to the fact that the genetic contribution to different mental diseases varies, or to other factors, is still to be explored. Given that the relation of genetics to the different diseases has not been equally exposed, it is surprising that attitudes are so uniform. Part of the explanation may be that all participants volunteered for genetic projects and presumably have more uniform attitudes toward genetics than a representative population of patients would have. Besides, the groups of persons suffering from bipolar disorder and schizophrenia may be too small for differences to show.

Intentions toward testing

A large majority of the participants in our study express an intention to test, thereby resembling samples questioned in other studies including persons with bipolar disorder or schizophrenia. In these studies, 75–99% of the respondents express positive attitudes toward psychiatric genetic testing (Smith *et al.*, 1996; Trippitelli *et al.*, 1998; Jones *et al.*, 2002; Delisi and Bertisch, 2006), and 77–89% express positive attitudes toward psychiatric genetic testing of children (Smith *et al.*, 1996; Trippitelli *et al.*, 1998; Jones *et al.*, 2002).

Fifty percent of the participants in our study support psychiatric genetic prenatal testing. Other studies asking directly about the participants' intentions to use psychiatric genetic prenatal testing report 29–56% of the participants expressing this intention (Trippitelli *et al.*, 1998; Jones *et al.*, 2002; Delisi and Bertisch, 2006). What is similar across studies is a weaker support for prenatal testing than for testing of children or self. Further, whereas we found no significant differences between the proportions of participants wanting psychiatric and somatic genetic testing themselves, participants in our sample show significantly less support for prenatal testing for psychiatric illness than for somatic illness. Smith *et al.* (1996) found similar attitudes and explain this difference with the fact that somatic illness may be perceived as potentially more fatal than bipolar disease. This 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.

Factors related to intention to test

The relatively large amount of the participants expressing an intention to test regardless of treatment possibilities indicate that testing is not just perceived as a way to better treatment. Similarly high levels of interest in psychiatric genetic testing even without preventive treatment options are found in another study (Smith *et al.*, 1996). We examined which factors were related to intentions to test, to understand some of the perceived benefits and barriers to test uptake.

Surveys conducted among the general public have reported interest in genetic testing to be related to gender, age, and educational level (Aro *et al.*, 1997); knowledge (Henneman *et al.*, 2006); and religious convictions (Schwartz *et al.*, 2000). We therefore included these variables in the model. Because different mental diseases have different consequences, we wanted to explore if attitudes toward testing differed depending on diagnosis. Further, as a central characteristic of genetics is that it involves not only the individual but also the individual's relatives, we wanted to explore if parenthood made a difference in attitudes toward testing.

Psychiatric genetics raises issues of stigma and of possible misuse of genetic information, and we therefore included variables measuring attitudes toward implications related to guilt, shame, and stigma and a variable assessing the participants' trust in psychiatric genetic researchers. Finally, perceived benefits and objections to testing have been shown to influence intentions (Henneman *et al.*, 2006), and we therefore entered variables measuring expectations toward testing into the model.

Intention to test only if effective treatment or prevention exists is obviously motivated by the prospect of better treatment or prevention of mental illness. In addition, having children seemed to be an incentive for seeking testing if effective treatment or prevention exist, as did the expectation to feel more prepared to fight the disorder when knowing of the presence of risk genes. Trust in researchers is also positively related to intention to test in our sample. None of the other variables of expectations and attitudes are associated with intention to test if treatment exists, indicating that the prospect of better treatment or prevention weighs more than fears of negative implications of research and testing. Intention to test regardless of treatment possibilities is, however, nega-

tively related to two variables measuring negative implications of research and testing. This difference indicates that if better treatment is not guaranteed, fears of negative side effects become important. Expecting to feel better prepared to fight the disorder when knowing of the presence of risk genes is the variable most strongly related to intention to test, indicating that perceiving psychiatric genetic knowledge as empowering will be an incentive to seek testing.

The results on factors related to intention to test allow us to present a tentative description of the possible candidates for testing. As the first psychiatric genetic tests seem to be tests with poor clinical validity and no prospect of better treatment, the typical consumers of these tests may be patients with a perception of genetic knowledge as empowering and with fewer concerns regarding negative implications of psychiatric genetic knowledge. The challenge now and in the future will be to offer balanced information about the validity and the pros and cons of genetic testing to these persons.

When tests with the prospect of better treatment or prevention become available, results indicate that having children will be an incentive to seek testing. These future counselees will most likely be interested in what kind of information their own genetic test offers concerning the risk of their offspring and the prospect of treatment and/or prevention.

Implications

To provide relevant information about genetics, it is necessary to know the expectations toward psychiatric genetics and whether these expectations match what genetics will be able to offer or may be too optimistic, mainly reflecting the hopes of the respondents. Results from this survey represent the attitudes toward psychiatric genetics among a large group of persons with different psychiatric diagnoses. Our sample represents a very well-described target group in relation to psychiatric genetics, and their attitudes, expectations, and intentions are relevant to the public debate, future policy-making concerning psychiatric genetics, and for developing educational programs concerning genetic innovations in medicine. This knowledge will also enhance the clinical validity of both present and future psychiatric genetic counseling (Austin and Honer, 2005).

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). It is therefore possible that the high numbers of participants in our study expressing intention to test may not mirror the actual future demand for psychiatric genetic testing. A recent study among persons with bipolar disorder show intentions toward testing to be dependent on the lifetime risk indicated by the test, and the authors suggest that previous studies that did not specify the lifetime risk imparted by the test may have overestimated the interest in testing (Meiser *et al.*, 2008). Following this, our results may be more indicative of the general acceptance 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 are relevant to the debate on mental illness and genetics.

Our results on factors related to intention to test indicate that a proportion of the persons intending to test will only do so if

they are certain the test will better their treatment possibilities, and therefore they may not apply for testing as long as clinical benefits are questionable. The persons wanting to test regardless of treatment possibilities may have other motives for testing, and a larger proportion of this group will probably do so before clinical benefits are obvious. As these persons focus on the expected empowering effect of genetic knowledge and may not be aware of possible negative side effects, balanced information about genetics is needed both in the mass media and in the context of psychiatric genetic counseling.

Our study has certain limitations. Although the sample for the initial genetic studies was recruited through a diversity of sources, the psychiatric hospital, psychiatrists, and advertisements in newspapers and on the Internet, all persons participating did initially volunteer for genetic projects, rendering it possible that the sample may be more in favor of psychiatric genetics than other psychiatric patients.

Besides this, a survey has certain intrinsic limitations. Participants can only answer the questions posed and do not have the opportunity to express either which further issues they consider important, or the reasoning behind their answers. Because the field of psychiatric genetics is relatively new, descriptive information is valuable, but a combination of the survey method with more exploratory methods is important. We developed the survey partly based on the results from a focus group study, and are now conducting additional focus groups with some of the survey participants to explore their perception of psychiatric genetics and their expectations regarding testing further.

Acknowledgment

This study was funded by a grant from Psykiatrisk Forskningspulje.

Disclosure Statement

No competing financial interests exist.

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