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Genetic Testing in Psychiatry: A Review of Attitudes and Beliefs

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Abstract

The advent of genetic testing for psychiatric conditions raises difficult questions about when and how the tests should be used. Development of policies regarding these issues may be informed in a variety of ways by the views of key stakeholders: patients, family members, healthcare professionals, and the general public. Here we review empirical studies of attitudes towards genetic testing among these groups. Patients and family members show strong interest in diagnostic and predictive genetic testing, and to a considerable extent psychiatrists share their enthusiasm. Prenatal test utilization seems likely to depend both on parental views on abortion and the seriousness of the disorder. Parents show a surprising degree of interest in predictive testing of children, even when there are no preventive interventions available. Many persons report themselves ready to alter their lifestyles and plans for marriage and family in response to test results. Respondents also fear negative consequences, from discrimination to being unable to cope with knowledge of their “genetic fate.” Empirical studies of beliefs about genetic testing suggest tests are likely to be embraced widely, but the studies have methodologic limitations, reducing the certainty of their conclusions, and indicating a need for further research with more representative samples.

Keywords

genetic testing; psychiatry; ethics

Introduction

Family studies have long demonstrated an hereditary component to various mental illnesses (Smoller et al., 2008). With recent advances in genetic knowledge there has been great optimism that genetic research will uncover mechanisms of psychiatric disorders and lead to newer and better therapies (Braff & Freedman, 2008). However, the advent of genetic testing in psychiatry has also raised many questions and concerns. First and foremost is the normative question of whether and under what circumstances (now or in the future) genetic testing should be pursued? Related to this are questions about how policies should differ for specific patient populations (fetus vs. child vs. adult). What should be done with the information- especially when the patient is asymptomatic? Should genetic information be treated differently than other health information? (Tsuang et al., 2001) Who may access

genetic tests, and who may access test results? Finally, there are empirical questions of whether patients (and physicians) will request genetic testing. If they do, how will patients respond to the results, particularly if they indicate a risk for psychiatric disorder?

The normative questions in this list require careful analysis of the moral considerations involved. However, development of policies regarding these issues may be informed in a variety of ways by the views of key stakeholders: patients, family members, healthcare professionals, and the general public. Although reports of attitudes and intentions do not always foreshadow actual behavior, they provide a window into the thinking of those persons most likely to be impacted by the spread of genetic testing for psychiatric disorders. Data on stakeholders' views can indicate a need for targeted education, identify areas in which regulation may be necessary, and generally indicate in which direction the moral sentiments of key portions of the population tend. Hence, there are sound reasons to explore attitudes and beliefs about genetic testing among relevant groups.

A number of empirical studies have attempted to do exactly that, examining what patients, families, and clinicians know and think about genetic testing in psychiatry. However these studies are scattered across different literatures, each study considering a limited number of questions and usually targeting a particular, often unique population. The present review is an attempt to synthesize these many reports to sketch a composite view of attitudes and beliefs regarding genetic testing in psychiatry, and to assess the implications of the data. We focus in particular on lay interest in genetic testing, psychiatrists' attitudes, beliefs about the benefits and risks of testing, attitudes towards prenatal testing and testing of children and adolescents, anticipated response to genetic testing, and views of direct-to-consumer testing for psychiatric disorders.

Methods

We searched PubMed using the keywords "psychiatry" and "genetic testing," limiting our results to English-language publications for a ten-year period through November 2010. This yielded 912 articles. Although many articles were not material to this review, some of these publications identified other relevant studies, which were added to our sample. We used the titles and abstracts to identify quantitative (n=17) and qualitative (n=6) empirical research articles focusing on attitudes and beliefs regarding genetic testing in psychiatric disorders. The study designs are summarized in Tables 1 and 2. We did not include articles discussing the technical aspects of genetic research or articles updating readers on genetic tests that are currently available. In addition, although psychiatrists often participate in treating neuropsychiatric conditions such as Alzheimer's and Huntington's disease, the many ways in which these disorders differ from traditional psychiatric disorders (e.g., average age of onset, course, and outcome), as well as their extensive consideration elsewhere in the medical literature, led us to exclude them from our systematic review; however, reference is made below to some of these studies for illustrative purposes. When statistical tests were reported by the original authors, the results are noted in the text below.

Interest in undergoing genetic testing

Survey respondents often show high interest in undergoing genetic testing for all types of medical disorders (Roberts et al., 2005), including psychiatric disorders, although the data for the latter come primarily from surveys of affected persons and their family members. For example, among family members of schizophrenia patients who had participated in genetic research, DeLisi and Bertisch (2006) reported that 83% would want to be tested if a genetic test for schizophrenia existed. In a mixed group of 90 bipolar patients (many of whom were enrolled in genetic research studies), 85% indicated that they would definitely be tested if a

genetic test for bipolar disorder existed, and another 15% said they would probably have the test (80% of their spouses indicated that they would want to be tested too) (Trippitelli et al., 1998).

Interest in genetic testing appears to be affected to some degree by the utility of the resulting information for prevention or treatment, and as well as the conclusiveness of the results. Laegsgaard et al. (2009) reported that many Danish patients would undergo genetic testing if treatment or prophylaxis were available: 35% of anxiety patients (n=105), 28% of bipolar patients (n=29), 46% of schizophrenia patients (n=35), and 51% of depression patients (n=228). But many others would be tested notwithstanding treatment possibilities (anxiety 41%, bipolar 55%, schizophrenia 31%, and depression 36%). Other studies indicate that interest is often associated with the degree of certainty a test offers. (Meiser et al., 2005; 2008) A survey by Meiser et al. (2008) of bipolar depressed or schizoaffective patients (n=105) and unaffected family members (n=95), all enrolled in genetic research, showed that if a positive test would indicate a 25% lifetime risk, 75% of patients and 79% of family members were probably or definitely interested; those figures increase to 91% of patients and 92% of family members for a 100% lifetime risk. The increasing interest as the test's predictive power increased was significant for both groups (signed rank tests 25–50% risk: $p<0.001$; 50–75%: $p<0.001$; 75–100%: $p=0.04$).

Of course, high rates of potential interest may not translate into widespread genetic testing. The best illustration of this difference comes from people at risk for Huntington's disease, of whom 40–79% express some intention to get tested, but only 9–20% actually utilize the test. (Meiser & Dunn, 2000) However, the previously noted differences between degenerative conditions such as Huntington's disease and most psychiatric disorders may limit the ability to extrapolate from these data to the disorders being considered here.

Psychiatrists' attitudes toward genetic testing

Support for genetic testing among psychiatrists varies by the circumstances in which the test would be used. Perhaps least controversial is genetic testing of symptomatic patients. Many psychiatrists attending a CME course on psychopharmacology (n=352) who were surveyed by Finn et al. (2005) said they would use genetic testing if it could help clarify a diagnosis in adult or child patients showing symptoms of schizophrenia (adults 75%, children 75%), bipolar disorder (74% and 72%), or panic disorder (66% and 63%) (differences between groups were not significant [n.s.]). In a survey of clinical psychiatrists in New York City (n=64) and psychiatric genetics researchers (n=162), if a genetic test for schizophrenia were available, 72% of psychiatrists and 70% of researchers responded that they would test all first episode patients and 73% and 69% would test all patients with chronic schizophrenia (differences between groups, n.s.), while 22% and 36% would test all psychiatric patients (chi-square, $p<0.05$) (DeLisi & Bertisch, 2006). If one person had a positive test, significantly more practicing psychiatrists (48%) than researchers (32%) would test the rest of the family (chi-square, $p<0.05$). Of note, 27% of psychiatrists and 30% of psychiatric genetic researchers would test no one (difference n.s.). We can only speculate about the cause of this relatively high enthusiasm for testing symptomatic patients, but it might be rooted in the assumption that they are likely to benefit from the swiftest and most accurate diagnosis available. Additionally, psychiatrists may believe that patients may feel less blame for their conditions if it is shown to have a genetic component.

Presymptomatic testing is more controversial, because in many cases little can be done to prevent or ameliorate the condition. Milner et al. (1999) reported that in a mixed sample of psychiatric faculty and residents (n=57), Alliance for the Mentally Ill members (n=65), and undergraduates (n=105), half of persons who suffered from mental illness and family

members, and a third of respondents who had a friend with a mental illness, said they would have wanted to know of the condition earlier in life. Psychiatrists, too, are divided over presymptomatic testing. If there were a genetic test with a high predictive probability (>95% chance of having a disorder given a positive test result), only a minority of psychiatrists attending a CME course said they would use it to test asymptomatic adults with a family history of schizophrenia (45%), bipolar disorder (43%), or panic disorder (29%) (Finn et al., 2005). However, other surveys have found higher rates of interest in presymptomatic genetic testing. In a survey by Jones et al. (2002), 69% of psychiatrist trainees (n=32), 79% of patients in a general practice setting (n=90), and 87% of bipolar patients (n=147, 2/3 of whom were enrolled in genetic research) approved of testing asymptomatic adults for bipolar susceptibility genes. Some of this variation among studies is likely due to varying perceptions of genetic risk, i.e., the likelihood that a person with an affected relative will also develop an illness. This was illustrated by a survey conducted through a Canadian website offering information on psychosis (n=116, estimated response rate 1.3%). The investigators found that 85% of respondents with affected family members viewed predictive genetic testing positively; however, testing was viewed positively by 91% who overestimated their genetic risk, as opposed to only 43% of those who underestimated their genetic risk (Austin et al., 2006).

Many situational factors affect physicians' beliefs about when genetic testing is appropriate. In a small survey of psychiatrists and other mental health professionals enrolled in a CME course on genetics (n=41), 80% approved of testing a 25 year-old patient who wanted to tell her fiancé if she was predisposed to Huntington's Disease (HD); 20% of testing a 16 year-old who wanted to tell her fiancé whether she will develop HD, but whose mother believes she is too young to know; 43% of testing a 16 year-old who is simply curious about her risk for HD and has her mother's support. Although caution is warranted in generalizing from these limited data, the maturity of the decision maker and the use to which the data will be put both appear to affect mental health professionals' views on the appropriateness of testing. In the same survey 80% approved of APOE*4 testing of a 50 year-old man whose mother has Alzheimer's disease and who is contemplating a major 10-year financial investment; and 60% approved testing a 21 year-old man whose grandfather died of Alzheimer's disease and who will give \$10 million from his inheritance to Alzheimer's research if he is predisposed himself (Mrazek et al., 2007). Again, the putative utility of the information to be obtained appears to play an important role in support for testing.

Beliefs about risks and benefits

Risks

Many studies have documented concerns about the risks of genetic testing. All of the American studies were conducted before implementation of the Genetic Information Non-discrimination Act (GINA) in the United States. One of the most commonly cited fears is that a positive genetic test will interfere with obtaining or keeping affordable health insurance (Meiser et al., 2005; Roberts et al., 2005; Trippitelli et al., 1998; Wilde et al., 2010). Concern about insurance in general was mentioned by 63% of affective disorder patients participating in genetic research (n=95) and their family members (n=105) (Meiser et al., 2008), by 73% of unaffected persons enrolled in genetic research on depression (n=128) (Wilhelm et al., 2009), and by 93% of psychiatrists at a CME course (Finn et al., 2005). Although GINA bans discrimination in health insurance coverage decisions on the basis of genetic information, other forms of insurance in the U.S. remain unregulated.

Worries about employment discrimination are also common (Meiser et al., 2005; Roberts et al., 2005; Wilde et al., 2010), shared by 65% of affective disorder patients and their family members (n=200) (Meiser et al., 2008), by 72% of unaffected persons in a genetic study

(Wilhelm et al., 2009), and by 78% of psychiatrists at a CME course (Finn et al., 2005). Of note, GINA does not eliminate such concerns, since employers can still obtain information about genetic predispositions from post-employment physical examinations, Family Medical Leave Act requests, medical records of employees covered by self-insurance programs, and casual discussions of family histories. Psychiatrists attending the CME course also believed genetic testing could lead to lowered expectations for children carrying high-risk genes (63%), movement of research and clinical resources away from psychosocial therapies (52%), denial of resources to symptomatic patients who do not carry high-risk genes (36%), increased stigma (35%), and elimination of desirable traits through genetic selection against genes associated with mental illness (33%) (Finn et al., 2005).

The effects on persons receiving test results also evoke widespread concern. Sixty-two percent of unaffected persons in a genetic research study expressed concern that a positive test result could make people feel stressed, depressed, or vulnerable (Wilhelm et al., 2009). 61% of affective disorder patients and unaffected family members thought it could increase suicide rates (Meiser et al., 2005; 2008). Among bipolar patients and their spouses, a substantial minority were concerned that a positive test would upset persons tested because of worries about their children or their spouses (Trippitelli et al., 1998). A smaller number were also concerned that a positive test would cause negative self-perceptions, making it harder to reach goals. An additional concern, mentioned in the qualitative literature, is the development of “fatalistic thinking” (i.e., being worried all the time, because of a belief that one will certainly develop the psychiatric disorder) (Wilde et al., 2010). Importantly, in DeLisi and Bertisch’s 2004 survey, 27% of psychiatrists and 33% of psychiatric genetic researchers thought that testing as part of genetic research on schizophrenia would have no adverse consequences (DeLisi & Bertisch, 2006); and in another study the vast majority of bipolar patients and their spouses said the benefits of knowing whether a person carried a predisposing gene for bipolar disorder outweigh the risks (Trippitelli et al., 1998).

A 2009 survey in Denmark suggests many concerns have not diminished as knowledge of the genetics of psychiatric disorders has advanced. Among 397 psychiatric patients with affective or anxiety disorders or schizophrenia, concerns were expressed by 39% that genetic research will bring too many difficult choices, will generate an attitude of some lives being worth more than others, and will foster work or insurance discrimination against at risk individuals (50%) (Laegsgaard et al., 2009).

Potentially tempering these concerns are data suggesting less-than-expected adverse impact of persons receiving results of genetic testing. Green et al. (2009), for example, reported on the generally benign psychological effects of disclosing APOE genotype. In the study, adult children of Alzheimer’s patients were invited to receive education and APOE testing (218 received education, 183 gave a blood sample). Participants were randomly assigned to receive their APOE results (n=111) or to have the results withheld (n=51). After 12-months (148 completed follow up) researchers had identified no difference in anxiety, depression, or test-related distress between the two groups, although those who tested positive for the risk factor had somewhat higher levels of distress than those with negative results. Similarly, a survey of more than 2000 participants in a study of direct-to-consumer genetic testing for non-psychiatric conditions found over 90% reported no psychological distress, and there was no significant increase in reported anxiety (Bloss et al., 2011).

Benefits

Many of the respondents in these surveys were optimistic that genetic testing would provide benefits. A common hope is that it will allow affected persons to obtain treatment to prevent relapses (Murphy & Thompson, 2009). This was endorsed by 68% of bipolar patients and spouses (Meiser et al., 2005) and by 83% of unaffected persons in a genetic study of

depression (Wilhelm et al., 2009). A related belief is that it will allow at-risk persons to avoid stressors or triggers (Meiser et al., 2005), an idea embraced by 89% of bipolar patients and family members (Meiser et al., 2008) and by 77% of unaffected genetic research subjects (Wilhelm et al., 2009). Psychiatrists at a CME course were optimistic that genetic testing would improve understanding of the biological basis of disease (91%), aid discovery of new and better treatments (79%), provide diagnostic clarification of affected patients (77%), identify presymptomatic patients at risk for illness (77%), allow targeting of resources to at-risk populations (74%), allow prenatal testing to guide reproductive choices (66%), and lead to destigmatization of mental illness (58%) (Finn et al., 2005). Regarding stigma in particular, 70% of a mixed group of psychiatric patients in Denmark believed spreading knowledge that mental disorders are partly genetic will make it less shameful to suffer from a mental disease, a view endorsed by significantly more depressed than bipolar patients (Laegsgaard et al., 2009). Other potential benefits cited by bipolar patients and family members include helping research (90%) and providing a basis for tailoring medications to specific mutations (92%) (Meiser et al. 2005; 2008). Eighty-four percent of unaffected persons in a genetics of depression study noted that testing could allow earlier diagnosis and intervention (Meiser et al., 2005; Wilhelm et al., 2009). Less commonly, respondents believed genetic information could help a person make important life decisions, especially regarding marriage (Meiser et al., 2005; Trippitelli et al., 1998), family planning (Austin & Honer, 2007; Meiser et al., 2005), and financial planning (Trippitelli et al., 1998).

In schizophrenia in particular, perceived benefits of genetic testing are somewhat more guarded. Thirty-five percent of family members, 40% of psychiatric genetic researchers, and 9% of psychiatrists expressed the belief that genetic testing will be used to develop new treatments. Even fewer family members (10%), psychiatric genetic researchers (21%), and psychiatrists (11%) thought genetic testing would allow early detection (DeLisi & Bertisch, 2006).

Attitudes and beliefs about prenatal genetic testing

Prenatal genetic testing for psychiatric conditions is particularly controversial, because—unless preimplantation genetic diagnosis is used—the only available intervention is abortion. Termination of pregnancy is a drastic step in such cases, considering that many fetuses with a “positive” genetic test have only a small absolute risk of illness, potentially of limited severity. One qualitative study of 21 members of families with high rates of bipolar disorder suggested that interest in prenatal testing is limited by several factors: personal opposition to abortion, optimism that new treatments will become available, and a belief that life involves so many risks that one additional risk factor might have little impact (Meiser et al., 2005).

Several quantitative studies have measured support for prenatal testing. In a 2008 Danish survey, 37% of patients with affective or anxiety disorders enrolled in genetic research (n=397), 41% of relatives (n=164), and 29% of medical and psychology students (n=100) were against the possibility of parents knowing their unborn child’s disposition for psychiatric disease (differences across groups, n.s.) (Laegsgaard & Mors, 2008). The same researchers reported in 2009 that 37% of a mixed group psychiatric patients opposed psychiatric genetic prenatal testing (Laegsgaard et al., 2009). A 1993 U.S. study of bipolar patients and their spouses found that 44% would definitely or probably test a fetus; 39% of patients and 42% of spouses would definitely or probably *not* test a fetus; and 17% of patients and 15% of spouses were uncertain (Trippitelli et al., 1998). In the U.K., Jones and colleagues reported in 2002 that 29% of bipolar patients and 35% of general practice patients approve of prenatal testing for bipolar susceptibility genes (Jones et al., 2002). Meiser et al. (2008), working in Australia, found more support, reporting that 54% of bipolar patients and 55% of unaffected family members were interested in prenatal testing

for bipolar disorder. Considering schizophrenia specifically, DeLisi and Bertisch (2006) reported that 56% of unaffected family members, 56% of clinical psychiatrists, and 25% of psychiatric genetic researchers supported prenatal testing (chi-square, $p < 0.001$).

Some evidence suggests opinions vary depending on the specific disorder for which the fetus is at risk. In a 1999 study by Milner et al. (1999), 85% of psychiatrists and residents at one department of psychiatry supported prenatal testing for bipolar disorder, 81% for schizophrenia, 75% for depression, 74% for obsessive-compulsive disorder, and 51% for panic disorder. A more recent survey of psychiatrists by Finn et al. (2005) showed different percentages but similar variability with regard to testing members of affected families and the general population respectively: affirmative responses were obtained from 58% and 14% for bipolar disorder, 70% and 19% for schizophrenia, and 35% and 10% for panic disorder.

Patients seem aware that the only recourse after prenatal testing is abortion (Austin et al., 2006; Meiser et al., 2005), and many are of the opinion that some conditions do not warrant it. For instance, in a 1993 U.S. study, a majority of bipolar patients (55%) and their spouses (65%) would definitely *not* abort a fetus carrying a gene for bipolar disorder (Trippitelli et al., 1998). In Sydney, only a minority of bipolar patients (25%) and unaffected family members (29%) would abort a similarly affected fetus (Meiser et al., 2008). Some psychiatrists at a CME course reported that they would advise abortion if a genetic test showed a high probability of developing autism (20%), schizophrenia (12%), antisocial personality disorder (10%), bipolar disorder (3%), major depression (2%), or alcoholism (2%); for comparison, 25% would advise aborting for Huntington's Disease, and 19% for Down syndrome (Finn et al., 2005).

Whether potential parents say that they would abort depends on the likely severity of the disease. One American survey reported that if a fetus was likely to experience a mild course of bipolar illness (one episode of mania and one episode of depression), few medical students (3%) ($n=35$), residents (10%) ($n=30$), or bipolar disorder support group members (4%) ($n=48$) would abort. But if a severe course was predicted (severe suicide risk, hospitalized 50% of patient's lifetime), most medical students (73%), residents (85%), and support group members (68%) would abort (Smith et al., 1996). Danish researchers presented a scenario in which the fetus was at risk of having a severe mental illness, which could not be controlled with medicine, would jeopardize the ability to take care of a family, include a risk of suicide, and result in disability retirement at the age of 45 (Laegsgaard & Mors, 2008). If prenatal genetic tests showed a 25% risk of this outcome, 38% of a mixed group of psychiatric patients would abort, as would 53% of unaffected relatives, and 41% of medical students (relatives > patients; O.R. 1.9, $p < 0.01$). If the risk were 75%, then 64% of patients would abort, along with 74% of relatives and 81% of medical students (more relatives, O.R. 1.6, $p < 0.05$, and students, O.R. 2.4, $p < 0.01$, than patients). In a second scenario, the child was at risk for a moderate mental illness, including two or three episodes of illness and one to three hospitalizations, but medical treatment would let the child live a near-normal life. If prenatal tests showed a 25% risk of this outcome, 13% of patients, 21% of relatives, and 8% of students would abort (relatives > patients, O.R. 1.8, $p < 0.05$, students < relatives, O.R. 0.3, $p < 0.01$). If the risk were 75% then 24% of patients, 37% of relatives, and 23% of students would abort (relatives > patients, O.R. 1.8, $p < 0.05$). It is worth recalling, though, that decisions in real-life settings may differ from those identified when people are asked to make hypothetical choices.

Testing children and adolescents

Genetic testing of children and adolescents has both advocates and opponents (Appelbaum, 2004; Campbell & Ross, 2004; Rhodes, 2006; Tsuang et al., 2001). In a qualitative study

among bipolar patients and family members, some thought testing would be helpful, allowing early identification of at-risk persons when treatments might be available to prevent or ameliorate the illness. Others would consider genetic testing only if children showed symptoms, since genetic testing has potential harmful effects (such as altering parents' behavior towards their child). Several would not test adolescents, believing the minor should make that decision upon reaching the age of consent (Meiser et al., 2005).

Quantitative surveys also suggest a variegated response to testing children and adolescents. Jones and colleagues (2002) reported in 2002 that 78% of bipolar patients and 61% of general practice patients in a U.K. sample supported testing children for bipolar susceptibility genes. This is similar to Trippitelli et al.'s 1998 report in which 78% of bipolar patients said minors should be tested for bipolar genes, although 13% were uncertain and 10% said minors should not be tested. In another study, most participants in a bipolar support group (83%), medical students (97%), and residents (90%) would test children if prophylactic treatment were available. But fewer (70% in a bipolar support group, 40% of medical students, and 58% of residents) would test children if this were not available (Smith et al., 1996). Among affective disorder patients and family members interested in testing their children, 30% would test at birth, 33% in early childhood, 27% would test between ages 10–17, and 9% would test at 18 years or older (Meiser et al., 2008).

In Laegsgaard et al.'s 2009 study of a mixed group of psychiatric patients in Denmark, a third of parents said they would test their own children only if effective treatment or prophylaxis existed (by diagnosis: anxiety 35%, bipolar disorder 24%, schizophrenia 34%, depression 46%). Another third would test their children notwithstanding treatment possibilities (anxiety 37%, bipolar disorder 31%, schizophrenia 34%, depression 26%). An important motivator for testing children is the belief that parents will feel less guilty about their child's mental disorder if it were shown to be primarily genetic, a view endorsed by 45% of participants with no significant differences across psychiatric diagnoses.

Psychiatrists are more cautious about testing children and adolescents than are the other groups examined. If a test with high predictive probability existed (>95% chance of having a disorder with a positive test result), less than half of Finn et al.'s (2005) sample would test an asymptomatic child with a family history of schizophrenia (47%), bipolar disorder (44%), or panic disorder (30%). In another study, only 19% of psychiatrists approved of testing children for bipolar susceptibility genes (Jones et al., 2002). If a genetic test for schizophrenia were available, 41% of clinical psychiatrists would test adolescents with social problems, and 20% would test all newborns (DeLisi & Bertisch, 2006). Compared with patients, family members, and other groups, psychiatrists may be more aware of the current limited benefits of genetic testing in psychiatry and more sensitive to possible negative sequelae.

Patients' responses to genetic information

Patients may have a variety of emotional responses upon learning their genetic risk (Hoop, 2008). Laegsgaard et al. (2009) reported that 30% of psychiatric patients feared being unable to cope emotionally with the results of a psychiatric genetic test (anxiety > bipolar disorder, O.R. 3.2, $p=0.013$; anxiety > depression, O.R. 2.8, $p<0.001$; schizophrenia > depression, O.R. 3.2, $p=0.021$). Thirty-two percent of patients believed learning about their genetic risk could bring on the mental disorder in question (anxiety > depression, O.R. 2.6, $p<0.001$), a concern that may be particularly intense for psychiatric disorders, where psychological stress can play a critical role in precipitating episodes. However, many believed knowing their genetic risk would help them feel more prepared to fight the disorder (anxiety 54%, bipolar disorder 59%, schizophrenia 62%, and depression 59%, (n.s.)). Whether the same

patients were likely to see test results as both stress-inducing and helpful in preparing for the future, or whether these represent two different populations with varying characteristics, is unknown but worthy of further exploration.

Five percent of respondents in Hoop et al.'s (2008b) survey of 45 U.S. psychiatrists reported that patients become more distressed when learning there is a genetic component to their mental illnesses, although 23% of psychiatrists reported patients tend to feel less distressed. In an Australian study, Wilhelm et al. (2009) tested the reactions of 84 unaffected persons prospectively, giving them questionnaires before revealing their 5-HTTLPR genotype (a putative marker for depression risk), and surveying them again at 2 weeks and 3 months post-disclosure. Patients with "high-risk" genotypes had higher distress levels after learning their results, both at 2 weeks and 3 months. However, there were no differences between groups in terms of test-related positive experiences. At 2 weeks and 3 months, 92% of patients felt pleased that they had learned their results, 8% were not sure, and none regretted learning the results.

Some patients report that they would use genetic test information as an impetus for lifestyle changes (Appelbaum, 2004; Austin & Honer, 2007). In a qualitative study using the 5-HTTLPR gene as a test case, many of the 36 unaffected participants in focus groups thought that knowing they had a genetic risk for depression would cause them to learn more about depression, increase their vigilance for symptoms, undertake preventive strategies, reduce their stress, improve their diet, exercise more, and limit their drug and alcohol intake (Wilde et al., 2009). Only some persons would consider taking prophylactic medication in response to genetic test results indicating risk (Hoop, 2008; Wilde et al., 2009). Smith et al.'s (1996) survey of 48 bipolar patients in a support group found high interest in prophylactic medication, but this interest was proportional to the anticipated disease severity or the likelihood of developing the disease. In DeLisi and Bertisch's (2006) study on schizophrenia, 71% of persons with affected family members would take preventive medicine, as would 56% of clinical psychiatrists (100% would prescribe it), and 45% of psychiatric genetic researchers (52% would prescribe it). Of note, while early intervention seems promising, there is no guarantee that early medication will change the outcome for schizophrenia (Corcoran et al., 2005). These findings should be interpreted cautiously: the study of a large sample of participants of direct-to-consumer testing for non-psychiatric disorders concluded that few changes in lifestyle or behavior resulted from the testing, confirming the difficulty of motivating behavioral changes. (Bloss et al., 2011)

For some people, genetic information would factor into their decisions about marriage and childbearing (Appelbaum, 2004; Finn & Smoller, 2006; Meiser et al., 2005). Even without genetic testing, family history has been known to affect these important decisions. Among website visitors with psychosis in the family who responded to a questionnaire, 23% said their family history motivated them to have fewer children or no children (Austin et al., 2006). Similarly, among 200 persons with a family history of bipolar disorder, about half of whom had an affective disorder themselves, 30% were less willing to have children as a result and 5% were unwilling; 65% reported no effect of their family history on their attitude towards childbearing (Meiser et al., 2007). When considering genetic testing specifically, 92% of bipolar patients and 79% of their spouses in Trippitelli et al.'s (1998) survey said they would still have married even if a blood test had detected a gene for bipolar disorder. In the same study, 55% of patients and 58% of their spouses said knowing they or their spouse had a gene for bipolar disorder would not have deterred them from having children. For persons with schizophrenic family members in DeLisi and Bertisch's (2006) sample, 38% would forgo marriage and childbearing if they had a positive genetic test for schizophrenia, although significantly fewer psychiatrists (9%) and psychiatric genetic researchers (3%) would recommend this.

Beliefs about genetic privacy

Most persons believe genetic information is different from other health information (Roberts et al., 2005), a view endorsed by the 2008 Genetic Information Nondiscrimination Act, despite the criticism of some commentators (Baruch & Hudson, 2008; Rothstein, 2005). A desire for strict confidentiality is the rule (Tsuang et al., 2001), with studies showing general agreement that employers (97% of respondents) and insurance companies (77%–94%) should not have access to genetic information (Baruch & Hudson, 2008; Laegsgaard & Mors, 2008; Roberts et al., 2005; Trippitelli et al., 1998). Opinions are more varied about whether doctors should be given genetic test results. In a 2007 Danish survey, 37% of psychiatric patients and 39% of unaffected relatives believed general practitioners should be informed of psychiatric genetic test results with or without patients' consent, while only 14% of medical and psychology students believed this (students < patients, O.R. 0.3, $p < 0.001$; students < relatives, O.R. 0.3, $p < 0.001$) (Laegsgaard and Mors, 2008). These numbers are less than those in a U.S. survey, where 75% of bipolar patients approved of notifying doctors of genetic test results (Trippitelli et al., 1998).

Open debate continues about whether to warn relatives when a high-risk gene is discovered (Appelbaum, 2004; Offit et al., 2004). In Laegsgaard and Mors' (2008) Danish survey on psychiatric genetics, 18% of patients, 19% of relatives, and 12% of medical and psychology students supported notifying relatives – without the permission of the tested person – when a pathological gene is discovered (n.s.). A small number of court decisions in the U.S. have suggested that physicians may have an obligation to warn offspring at high risk of inherited conditions or at least to encourage patients to inform relatives at risk of the need for testing (*Pate v. Threlkel*, 1995; *Safer v. Pack*, 1996). Such duties appear more likely to be found when the conditions in question can be fatal and when preventive interventions exist. But the law is too fragmentary at this point to predict the dimensions that duties to warn will ultimately assume (Clayton, 2003).

A related concern is whether a person should ever be *required* to undergo genetic testing for psychiatric disorders. In the Danish survey, 95% of respondents believed that people have the right *not* to know their risk genes, with no significant differences among patients, relatives, and medical and psychology students (Laegsgaard & Mors, 2008). In the same study, though, 14% of subjects believed family members of psychiatric patients should be obliged to test for the disease (differences across groups, n.s.), 38% supported psychiatric genetic testing of soldiers (students < patients, O.R. 0.5, $p < 0.01$; students < relatives, O.R. 0.5, $p < 0.01$), and 46% supported testing persons occupying high-responsibility jobs (students < patients, O.R. 0.4, $p < 0.01$; students < relatives, O.R. 0.3, $p < 0.001$; relatives > patients, O.R. 1.6, $p < 0.05$). Twenty-two percent supported testing persons who want to adopt (students < relatives, O.R. 0.3, $p < 0.01$; relatives > patients, O.R. 1.7, $p < 0.01$), and 19% supported testing children given up for adoption (students < patients, O.R. 0.3, $p < 0.01$; students < relatives, O.R. 0.2, $p < 0.01$) (Laegsgaard & Mors, 2008).

Special considerations for psychiatrists

Several surveys have considered issues specific to psychiatrists. Most psychiatrists (78%–95%) reported that discussing genetic information with patients and families is a part of their role (Finn et al., 2005; Hoop et al., 2008b). However, not all psychiatrists feel confident about their genetic knowledge (9%–70%) or ability to offer and interpret genetic tests (Finn et al., 2005; Hoop et al., 2008b; Laegsgaard & Mors, 2008). A genetics quiz given as part of Finn et al.'s (2005) survey of CME attendees justified these misgivings: just 16% of psychiatrists answered at least half of the questions correctly, and 18% answered all nine questions incorrectly. Changes are afoot though. In Hoop et al.'s (2008b) small survey,

40% of psychiatrists reported having some genetics training in the last five years (22% within the last 2 years). Nevertheless, in a national survey of chief residents in 2008 (n=80), 15% said their residency included no training in genomics, and 35% received just 1–3 hours of training during residency (Winner et al., 2010).

Although psychiatrists do not question the importance of genetics in psychiatry (87% routinely take detailed family histories) (Finn et al., 2005), many seem unconvinced that genetic testing will have an impact on the field (Mitchell et al., 2010). Indeed, 42% of psychiatrists in Hoop et al.'s (2008a) study believed the development of genetic tests would have little effect on how most psychiatrists practice, and 14% believed the development of such tests would be irrelevant to their own work. Only half of psychiatrists (44%–53%) thought it would be “extremely useful” to have tests that would determine: 1) a patient's optimum dose of many psychiatric medications; 2) whether a patient is at high risk of serious side effects from a psychiatric medication; 3) whether a patient with mental illness is likely to have a severe course; or 4) whether an asymptomatic person is at high risk of developing a mental illness in the future (Hoop et al., 2008a). Of interest, psychiatrists with recent genetic training were *less* likely to believe these tests would be useful. These beliefs, coupled with gaps in psychiatrists' knowledge base, make it unsurprising that very few psychiatrists refer patients for genetic testing or counseling (80% of psychiatrists ordered no genetic tests from 2002–2006, according to Hoop et al. (2008b)); 71% of respondents in the Finn et al. survey (2005) had not referred patients for genetic counseling in 2001.

Attitudes toward direct-to-consumer testing

Many survey respondents support personal access to genetic information. Mrazek et al.'s survey of a small sample of mental health professionals found that 98% believed adults generally have a right to know their genotypes (Mrazek et al., 2007). Even more specific to psychiatry, Danish researchers found that 70% of psychiatric patients, 66% of their relatives, and 54% of medical and psychology students believe everyone should have access to psychiatric genetic testing (Laegsgaard & Mors, 2008). However, although hard data on utilization of direct-to-consumer tests are not publicly available, it appears that the enthusiasm expressed in surveys has not translated into support for recent business ventures offering genetic testing to anyone willing to pay (Hoop et al., 2008a; Mitchell et al., 2010). Once again, the apparent discrepancy between opinions offered in response to hypothetical questions and actual behavior is striking. At least one qualitative study (using the 5-HTTLPR gene as an example) reported that participants were unanimous in their disapproval of direct-to-consumer predictive genetic testing. Their objections included concerns about the credibility of the testing services, worries about the security of DNA samples and the privacy of genetic information, and lack of confidence in non-face-to-face genetic counseling (Wilde et al., 2010).

Conclusions

Several trends are apparent from the studies reviewed here. Patients and family members of persons with mental disorders show a high level of interest in diagnostic genetic testing, and to a considerable extent psychiatrists share their enthusiasm. However, the data for both groups are based largely on projections regarding future genetic tests, rather than on tests currently available. Similar conclusions apply to predictive testing, where for many respondents, interest is linked to the possibility of future effective prophylactic interventions. At the same time, these generally positive views are moderated by fears of negative consequences, ranging from concerns about discrimination to worries about being unable to cope with knowledge of what may be seen as one's “genetic fate.” That several studies have found that psychiatrists who know more about genetics are less likely to

endorse the value of testing suggests the need for greater education of both patients and health professionals on the uses, limits, and potential negative consequences of genetic testing. The extent to which psychiatric genetic testing is embraced in the future is likely to depend on the success of these educational efforts, over and above the strict clinical utility of the tests themselves.

Prenatal and childhood testing evoke mixed reactions. With abortion currently the sole recourse for positive findings from prenatal tests, such test utilization seems likely to depend both on parental views on abortion in general and on the seriousness of the disorder at issue. Family members' lived experience with psychiatric disorder appears to make them more responsive to the possibility of abortion, whereas patients—perhaps for obvious reasons—are less likely to endorse this approach. A surprisingly large proportion of parents say that they would test their children predictively even in the absence of prophylactic interventions, perhaps indicating a need for intensive genetic education for this group. In contrast, psychiatrists are much more reticent about testing children, displaying a greater recognition that the information—for the foreseeable future—is likely to bring few rewards and considerable risks for the child.

Few data exist on the real-life consequences of genetic testing, though surveys show that many persons report themselves ready to alter their lifestyles, marriage plans and expectations of having children in response to test results. Only a few studies in psychiatry have examined disclosure of actual results to tested persons, and the results were relatively benign. But whether that would be true for highly predictive tests of more severe disorders is simply not clear. More data on this question are badly needed. Despite well-documented fears of negative consequences from testing, such as insurance or employment discrimination, no studies have examined the extent of discrimination for psychiatric disorders *per se*, and there are limited data even regarding non-psychiatric conditions (Bombard et al., 2010; Kass et al., 2007; Peterson et al., 2002).

As genetic tests for diagnosis of and predisposition to psychiatric disorders become more widely available, questions inevitably arise about regulatory and liability concerns. In the U.S., federal authorities have taken a relatively hands-off attitude toward genetic testing. Although tests performed for clinical purpose must be conducted in laboratories certified under the Clinical Laboratory Improvement Act (Rivers, et al., 2005), the federal government has not otherwise regulated the accessibility of genetic testing—in contrast to many European countries that have enacted tight restrictions (Grimaldi, 2010). At the moment, it is unclear whether the Food and Drug Administration will exert regulatory authority over direct-to-consumer testing, and if so, what limits it will impose (Vorhaus, 2011). However, it does seem clear that if testing for either diagnostic or predictive purposes advances to the point that it represents the standard of care in psychiatry, clinicians who fail to obtain such tests may be held liable for negligence (*Molloy v. Meier*, 2004). This underscores the importance of clinicians staying up-to-date on advances in genetic testing and the clinical use of such tests.

The limitations of the studies reviewed here are substantial. Samples of patients, family members, and healthcare professionals who were interviewed or surveyed were generally small. Moreover, many studies relied on convenience samples, surveying patients from a single clinic or physicians from the authors' departments or hospitals. Much of the recent empirical literature has been generated by just a handful of very productive authors, whose results have yet to be replicated in other locations. Perhaps even more problematic, patient and family samples were frequently drawn from persons already engaged in genetic research, whose attitudes and beliefs about genetics may not be typical of other patients, family members, or the general public. Hence, our ability to generalize from the current data

is poor. Further complicating the situation is the absence of statistical comparisons in many studies and the failure, even when statistical tests are used, to control for possible sources of covariation (e.g., age, race, education).

To better understand the likely uptake of genetic testing for psychiatric disorders; the challenges facing patients, families, and physicians in interpreting the data; and the consequences of testing—both positive and negative—better-designed studies will be required. Future efforts should be based on large, representative samples, drawn from populations that have not participated in genetic research, with clearly defined hypotheses that are subject to appropriate statistical comparisons. Also missing from the literature are frank dialogues about the role that professional and popular opinion should play when formulating policies on psychiatric genetics. The most widely endorsed opinions are not necessarily the wisest. Especially concerning is the possibility that many views may be based on misinformation about what genetic testing offers. As research on the genetics of psychiatric disorders opens the door to increased use of genetic testing for predictive and diagnostic purposes, consideration of the data and their implications will be essential to the development of rational policy and practice.

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Table 1

Quantitative surveys of beliefs about genetic testing in psychiatry

Authors	Year	Subjects	Location
Smith et al.	1996	Members of a national bipolar support group (n=48), medical students (n=35), residents (n=30)	San Francisco
Trippitelli et al.	1998	Bipolar patients and their spouses (n=90) who were participating in a genetic linkage study, members of the Depression and Related Affective Disorders Association, or being seen in the affective disorders division of Johns Hopkins Hospital	Baltimore
Milner, Han, & Petty	1999	Faculty and residents of the University of Michigan Health System (n=57), members of the Alliance of the Mentally Ill (n=65), and undergraduates at the University of Michigan (n=105)	Ann Arbor
Quaid et al.	2001	Patients with bipolar disorder in a mood disorders clinic or a bipolar support group (n=31)	Indianapolis
Jones et al.	2002	Bipolar patients in a family study (n=97), consecutive bipolar patients at a lithium clinic (n=50), consecutive patients at a general practice clinic (n=90), psychiatric trainees in a masters level course (n=32)	United Kingdom
Finn et al.	2005	Psychiatrists attending a psychopharmacology course (n=352)	Boston
DeLisi & Bertisch	2006	Persons with 2 schizophrenic relatives who participated in a genetic research study (n=48), clinical psychiatrists belonging to a state psychiatric society (n=64), psychiatric genetic researchers attending a scientific meeting (n=162)	New York
Austin, Smith, & Honer	2006	Unaffected persons with a relative suffering from psychosis, recruited via a website offering information on psychosis (n=116)	British Columbia
Mrazek et al.	2007	Healthcare professionals attending a psychiatric genomics course at the Mayo Clinic (n=31 psychiatrists, 3 nurses, 1 social worker, 1 psychologist, 2 researchers, 3 "other")	Rochester, Minnesota
Meiser et al.	2007	Participants in the Molecular Genetics Study of Bipolar Disorder (n=95 affected, and n=105 unaffected persons)	Australia
Laegsgaard & Mors	2008	Participants in a psychiatric genetic research studies on depression, panic disorder, and psychotic disorders (n=561), depressed patients (n=149), relatives (n=164), medical and psychology students at a single university (n=100)	Denmark
Hoop et al.	2008a	National sample of US psychiatrists (n=45) drawn randomly from the AMA masterfile.	US
Hoop et al.	2008b	Same sample as Hoop et al. 2008a	US
Meiser et al.	2008	Participants in a genetic study of bipolar disorder (n=90 with an affective disorder, n=105 without)	Australia
Wilhelm et al.	2009	Participants in a longitudinal cohort study on depression (initially recruited from a postgraduate teacher training program) who requested to know their 5-HTT genotype	Australia
Laegsgaard, Kristensen, & Mors	2009	Participants in psychiatric genetic research projects with anxiety disorders (n=105), bipolar disorder (n=29), schizophrenia (n=35), or depression (n=228)	Denmark
Salkovskis et al.	2010	Persons walking down a street in Oxford, UK (n=120)	Oxford, UK
Winner et al.	2010	Psychiatry chief residents in US and Canada (n=80) whose emails were on record at the APA	US and Canada

Table 2

Qualitative studies of beliefs about genetic testing in psychiatry

Authors	Year	Subjects	Location	Study design
Campbell & Ross	2004	Genetic professionals (n=13) and pediatricians (n=12) from multiple institutions and parents (n=102) in the Chicago area	Chicago	Semistructured interviews with healthcare professionals, and focus groups with parents
Meiser et al.	2005	Participants in a study on the molecular genetics of bipolar disorder (n=22)	Australia	Individual interviews and focus groups
Wilde et al.	2009	Persons selected by a market research company to have evenly mixed gender, age, and socio-demographic backgrounds (n=36)	Australia	Focus groups
Murphy & Thompson	2009	Persons recruited from flyers posted in the community, most non-Hispanic blacks with depression/anxiety (n=26)	New York	Focus groups
Laegsgaard et al.	2010	Participants in a genetic study on depression (n=17)	Denmark	Focus groups
Wilde et al.	2010	Same sample as Wilde et al., 2009	Australia	Focus groups