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PSYCHOLOGICAL EFFECTS OF GENETIC TESTING FOR PSYCHOLOGICAL DISORDERS

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Abstract. Research aimed at identifying genes contributing to the aetiology of psychological disorders is in progress. This raises the possibility that genetic testing for such genes might become available. In this paper the possible psychological consequences of genetic testing for psychological disorders are examined. It is proposed that genetic testing may cause psychological and behavioural reactions that actually increase the person's risk of developing a psychological disorder or may maintain existing problems. It is also suggested that cognitive-behavioural models may be able to aid prediction of some of the likely consequences of testing and identify people who are likely to react in particularly negative ways to news of their genetic risk. If genetic tests for psychological disorders are developed, it is important that research is carried out into the psychological and behavioural effects of testing and ways of minimizing adverse effects, before such tests become widely available.

Keywords: Cognitive-behavioural, genetic, genetic testing, high risk, predictive testing.

Introduction

It is likely that genetic factors contribute to some extent to psychological disorders, and it has been suggested that in the near future many relevant genes may be identified (see Farmer and Owen, 1996, Rutter and Plomin, 1997 and Gelernter and Crowe, 1997 for discussions of current findings). Such developments may have important implications for our understanding and treatment of psychological disorders. However, there are also reasons for caution. The emphasis on identification of genetic factors could lead to other aetiological and maintaining factors being relatively ignored, even though these may be more amenable to intervention. Furthermore, advances in genetics will introduce the possibility of genetic testing for vulnerability to psychological disorders, raising a number of ethical and psychosocial issues. Some of these issues concern the possible effects of testing on the individual and their family. The question of whether or not genetic testing should be widely available (and whether a particular individual should undergo testing) should take into account the anticipated costs and benefits to the person tested. Examination of these issues regarding testing should begin now, at a relatively early stage, because it is possible that once relevant genes are identified

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there will be demands for testing to be quickly introduced. Consideration of the psychological effects of genetic testing also raises issues relevant to current practice, since some mental health professionals already provide clients with estimates (or general judgements) of the importance of the genetic component of their current problem. This paper is intended to highlight and discuss some of the possible effects of providing genetic information about psychological disorders.

It is important that mental health professionals have an understanding of the possible psychological effects of providing people with information concerning the genetics of psychological disorders. In terms of general policy regarding testing, mental health professionals will have a major role to play in providing recommendations about the extent to which genetic testing (if technically feasible) should be available and the context in which it should be offered (e.g. whether the offer of pre- and post-test psychological assessment and help should be mandatory).

An understanding of the impact of genetic testing will also be important in a number of ways to the practice of mental health professionals. Firstly, mental health practitioners are already being asked to advise geneticists about the psychological state of people who are contemplating testing for psychological and non-psychological disorders. At present, some people are refused testing in research settings if they are judged to be at high risk of severe psychological disturbance after testing (e.g. Tyler, Ball, & Crauford, 1992). Bloch, Fahy, Fox and Hayden (1989) report postponing testing for Huntington's Disease (a neurodegenerative disorder) in a candidate who had "a positive suicidal history, a positive score on the SCL 90(R) as well as moderate to severe depression on the BDI". This need for expert opinion regarding people's anticipated ability to cope with genetic information will increase as genetic testing becomes more widespread. When the test is designed to detect vulnerability to psychological problems, the issue may become yet more complicated, since people who are known to have psychological problems or vulnerabilities – a group previously excluded from genetic testing – may now be among those viewed as being particularly suitable for testing, in so far as they are more likely to have the genes in question. Secondly, patients who are undergoing therapy may consider testing and the therapist may have considerable influence over the decision whether or not to be tested. Thirdly, therapists are already being asked to help people cope with the news of their genetic risk for disease and the need for this kind of help will increase as testing becomes more widely available.

There are many ethical and social issues raised by the prospect of genetic testing for psychological disorders, but here we will focus on the possible psychological and behavioural effects of testing. Previous research findings concerning testing for Huntington's Disease will be described, as this is the only disease with psychological symptoms for which there is a body of research about the effects of genetic testing. The extent to which these findings are likely to generalize to other types of genetic testing will be discussed. We have a particular interest in the different types of responses to testing, as opposed to the "mean" effect shown by the group tested as a whole. Individual differences in reactions to genetic testing will be discussed with reference to our previous work in non-genetic health testing. In this paper we will only consider the testing of adults and will not consider the case of mental retardation and child onset problems.

Psychological reactions to an *increased*-risk result from genetic testing

After genetic testing for Huntington's Disease (HD), psychological reactions include shock, anger, pessimism about the future, depression, increased preoccupation with HD, guilt about possibly passing on the gene to their children, finding the result an emotional burden, continued feelings of uncertainty and even suicide attempts (e.g. Tyler, Morris, et al., 1992; Codori & Brandt, 1994; Tibben, Roos, & Niermeijer, 1997). All of these reactions can be expected after genetic testing for other psychological disorders. However, the reactions of those receiving a high-risk result from genetic testing in HD have generally been less severe than expected. It is tempting to conclude that the same will be true for other types of genetic testing, but there are several reasons why this may not be so. Firstly, HD is a dominantly inherited disorder with 100% penetrance, so that someone with a parent with HD has a 50% chance of having the gene, and people with the gene will all develop the disorder, if they reach the age of onset. This means that genetic testing allows the individual who has a family history of HD to move from uncertainty to relative certainty (whether good or bad news), which may help to reduce distress. This will not be the case for genetic testing involving multifactorial disorders, in which there are both genetic and non-genetic causal factors – here uncertainty may actually be increased after testing. For example, a positive genetic test result for a multifactorial disease may increase the estimate of a person's risk from 1% (population risk) to 30%. If they are found to have the relevant gene, the odds are still in favour of them *not* developing the disease, but the uncertainty is now greater. Another reason why it should not be assumed that genetic testing for other disorders will have similar effects to those reported after HD testing is that people who have undergone testing for HD in research settings have received extensive pre- and post-test counselling. It is not known what the psychological consequences would be if it was not possible to give this amount of counselling (as will be the case in most clinical settings). Furthermore, people who have current psychological problems or signs of vulnerability to them are generally excluded from genetic testing, so little is known about the likely effects of testing these patients (e.g. Tyler, Ball, et al., 1992; Tibben, Timman, Bannink, & Duivenvoorden, 1997). People who accept testing for HD also seem to be a self-selected group; they are less likely to anticipate negative emotional reactions than those who refuse testing (Codori, Hanson, & Brandt, 1994) and have high levels of resourcefulness (Bloch et al., 1989). Finally, it should be noted that Tyler, Morris, et al. (1992), Wiggins et al. (1992) and others report that some people refused to take part in follow-ups because they were too distressed (e.g. 17% of Tyler, Morris, et al.'s increased risk group), which indicates that the degree of psychological distress in those who receive a high risk result from HD testing may be higher than is generally reported.

There is a need for research into how people who are known to be at increased risk react if they become symptomatic. It has been reported that some HD carriers who initially coped well after testing have become severely depressed and suicidal when they develop symptoms of HD (Tibben et al., 1997). There is also a need for data concerning the psychological consequences of reaching the expected time of onset for people who know that they are at increased risk. Many of those tested for HD are not at the expected age of onset at the time of the test result and the follow-up data are not yet

available. It is important to note that HD has a later mean onset than psychological disorders such as anxiety disorders, mood disorders, eating disorders and so on. Many of the people tested for these psychological disorders will already be at or near the typical age of onset, which could result in more severe psychological reactions. This is partly because of the meaning of the result (i.e. they are facing an immediate rather than delayed threat of illness) and partly because these people's response to testing may already be *directly* influenced by their genetic vulnerability. It has been well documented that adverse life events are associated with an increased risk for many psychological disorders, particularly if the individual has a pre-existing psychological vulnerability (e.g. Brown & Harris, 1989), and receiving a high risk test result will be an adverse event for many people. The stress of the genetic test result could prove to be an aetiological factor in the person's first episode of the illness in question.

People who are at high genetic risk for psychological disorders are also likely to be at increased environmental risk. At times, a parent with a psychological disorder may not be able to give their child the level of care that they would otherwise have been capable of, and in some cases the child may as a result develop maladaptive coping strategies or negative beliefs about themselves. This means that some people whose parents have psychological problems may already be more at risk for psychological disorder than their genetic risk would indicate and may react particularly badly to news about their genetic risk.

An increased-risk result is likely to have effects on interpersonal relationships. In HD testing it has been found that partners of a gene carrier report increased psychological distress after risk notification which is still apparent three years later (Tibben et al., 1997) and couples in which one partner has received a high-risk result report lower marital satisfaction than couples who received a low-risk result (Quaid & Wesson, 1995). Byrne and Bamforth (1994) report a case where a woman with a high-risk result became depressed and reported suicidal preoccupation after her fiance called off the marriage because she had the HD gene. It is likely that in some cases the person with a high-risk result will feel guilty about being a current or future burden to their family or about possibly passing on the gene in question to their children, which may cause relationship difficulties. They may also feel anger towards the parent who passed on the gene in question. There may be problems outside of the family too: the person may face discrimination from others, since there is much prejudice about psychological problems in Western societies.

It is important to remember that even a high risk result can have benefits; Codori and Brandt (1994) found that patients who have received a high risk result from HD testing reported at least one positive effect of testing. However, many of these effects (e.g. relief of uncertainty and ability to plan for the future) may only apply to conditions such as HD where there was great uncertainty before testing, which is reduced by the test result. Some people who have already suffered psychological problems (or who go on to experience difficulties in the future) may feel that simply understanding more about the possible causes of their problems is beneficial. An increased-risk result for a multifactorial disease could have long-term positive psychological effects if the patient receives earlier diagnosis or treatment as a result or if they receive help to prevent episodes of psychological problems.

Psychological implications of *decreased*-risk test results

After a "low risk" result from genetic testing for HD, various positive psychological effects have been reported, including relief of uncertainty, reduction in "symptom-searching", relief from worry about their children's risk and improved ability to plan for the future (Codori & Brandt, 1994). However, there are difficulties for some of those who receive a low-risk result. Some feel guilty about those relatives who receive a high risk result (Codori & Brandt, 1994). Some who were expecting a high risk result found it difficult to adjust to the unexpected news. Problems in adjusting may be a particular problem for those who have made major life decisions based on the expectation that they would also develop psychological problems, such as not having children (Huggins et al., 1992). These types of problems may also occur in genetic testing for other psychological disorders.

An important feature of genetic and non-genetic health testing is that a negative or low-risk result is not always completely reassuring (e.g. Tibben et al., 1992; Rimes, 1996). For example, Tibben et al. (1992) found that 56% of non-carriers in their group remained preoccupied with the threat of HD and 44% sometimes questioned the reliability of the test. For multifactorial disorders, a decreased-risk result is even less reassuring, because someone who does not have a particular gene may still be at a considerable risk for the condition. Thus one of the often-cited advantages of health testing – reassurance – may be very limited after tests for multifactorial psychological disorders.

In genetic testing for multifactorial psychological disorders there are further possible negative psychological consequences. For example, if a person is found to be a low genetic risk but has suffered from the problem anyway or goes on to suffer it in the future, they are likely to consider why this has happened. If they cannot blame their genes, they may blame their environment, for example, poor parenting. This may cause more problems in their relationships with their parents than a genetic causal attribution would have done, because genes are likely to be perceived as less under the parents' control than their style of parenting. Alternatively, the person may consider that there is something intrinsically wrong with them as a person; for example, that they are somehow weak or defective. Since poor self-image is a risk factor for psychological problems, this type of attribution will increase their risk of persistent psychological distress (Abramson, Seligman, & Teasdale, 1978).

Testing people with a current psychological disorder

Genetic testing of people with a current psychological illness poses particular problems. It is likely that these people will have fewer resources with which to cope with the testing process and may respond to testing in ways that increase their distress. For example, there is evidence that people who tend to be anxious selectively attend to threatening information and are more likely to interpret ambiguous situations in particularly negative ways (e.g. Mathews & MacLeod, 1986; Clark et al., 1988; McNally & Foa, 1987), so it is likely that they will be more distressed by genetic testing than people without anxiety problems. Similarly, people suffering from depression may tend to view bad news from a genetic test as further evidence that the future is hopeless.

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Such hopelessness may prolong the depression and increase the risk of suicide. In the case of addictive behaviours, news of increased risk may result in beliefs such as "there's no use trying to fight it [the urge to use the substance], it's in my genes" – which could facilitate further abuse of the substance in question. Someone with an addiction may also use the substance to help them cope with the distress caused. Many people with psychological problems have low self-esteem and they may conclude that the results of a genetic test confirm their low opinion of themselves; this will probably have the effect of maintaining or worsening their problems. For all psychological problems, an increased risk result may cause fatalistic attitudes towards their current problems and decrease their motivation to try to resolve their difficulties. Research is needed to examine the extent to which these kinds of responses occur after genetic testing.

In previous genetic testing research, attempts have been made to avoid these kinds of problems by excluding people with current psychological problems from the testing process. At the present time it does not appear that there are clear treatment benefits in testing patients who are currently suffering from psychological problems, although this situation may change. If such patients are to receive testing, effective ways of providing psychological support need to be developed and evaluated. Testing could then be offered in combination with psychological support at every stage from trained professionals. Each patient should receive pre-test assessment from a professional who should identify the type of reactions that the patient is likely to experience, determine whether the patient is likely to be able to cope with the testing process, help the patient to decide whether they definitely want to be tested, and help prepare the patient to deal with the test result. If testing of people with current psychological problems does occur, this should initially take place in research settings so that the impact of testing and the effectiveness of psychological support can be evaluated.

Individual differences in reactions to medical tests

There is a need for theoretical models of psychological reactions to genetic testing. Such models would allow the generation of hypotheses regarding factors that determine how different people react to genetic testing. An understanding of such factors would inform the development of methods for preventing and reducing distress associated with testing. Furthermore, if genetic testing for psychological disorders becomes widespread there will be insufficient resources to offer everyone intensive pre- and post-test counselling. If factors that determine individual differences in reactions to testing were better understood, it may be possible to use pre-test assessments to identify people who are at relatively higher risk of suffering adverse psychological effects, and target counselling resources at these people. We have proposed that a cognitive-behavioural (CB) model of health anxiety can be usefully applied to the assessment and prediction of different responses to predictive testing for physical illness (Salkovskis & Rimes, 1997). One reason why this model seems particularly promising is that it has given rise to an intervention for health anxiety that has been shown to be effective in controlled trials (e.g. Warwick, Clark, Cobb, & Salkovskis, 1996).

The CB model (e.g. Warwick & Salkovskis, 1990) hypothesizes that some people become excessively anxious about their health because they have (a) maladaptive general beliefs about health, illness and related matters and (b) specific beliefs about

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particular signs, symptoms and illnesses; these factors lead them to interpret medical information or symptoms in a particularly negative way. Examples of problematic general beliefs about health are ''I'm certain to die young because I'm very similar to my mother, who died in her forties'' or ''Bodily changes are always a sign that something is wrong''. Specific beliefs that will largely determine the degree of anxiety about a particular disease are those concerning (a) the perceived probability of developing the disease; (b) the perceived seriousness of the consequences of that disease; (c) the perceived ability to cope if that disease developed; and (d) the perceived availability of methods of prevention or treatment (or other external sources of help). Further factors then maintain the pattern of negative thinking and anxiety. These factors include: (a) selective attention to threatening stimuli such as media reports about the disease or bodily sensations that could be interpreted as symptoms of disease; (b) inappropriate and excessive checking (such as repeated examination of the body for symptoms); and (c) excessive reassurance seeking (e.g. frequent visits to doctors). If this hypothesis is correct, it should be possible to identify people who are likely to make the most negative interpretations of predictive test results and who will therefore become the most distressed, by assessing both general beliefs about health, specific beliefs about the disease and the implications of the test, and whether the person tends to react to health threats with behaviours that may maintain their anxiety.

In a previous prospective study (Rimes, 1996; Rimes & Salkovskis, in preparation) we applied a CB model of health anxiety to the understanding and prediction of psychological responses to bone density measurement, which gives an indication of one's future risk for osteoporosis. This is a multifactorial disease and the reactions to this type of predictive testing may have some similarities to predictive genetic testing for multifactorial diseases. The main findings of our study were:

(1) After a ''high risk'' result, women who reported high levels of pre-existing general health anxiety showed an immediate increase in anxiety about their bone density. At the 3 month follow-up these women were still significantly more anxious than women who also received a ''high risk'' result but who don't tend to worry about their health. These two groups had not differed in their ratings of anxiety about bone density before the scan;

(2) After a ''low risk'' result, women who report a pre-existing tendency to worry about their health were only temporarily reassured. Their ratings of anxiety about their bone density and perceived likelihood of developing osteoporosis decreased immediately after the low risk result but then showed a significant increase by the 3 month follow-up (at which point their ratings were not significantly different from those of women who received a high risk result but who had low levels of pre-existing general health anxiety);

(3) Factors derived from a CB model were significant predictors of distress after the scan. Three types of factor predicted distress in response to screening; (a) a pre-test general tendency to misinterpret ambiguous health-related stimuli in a threatening way; (b) specific negative beliefs about osteoporosis; and (c) maladaptive behavioural responses to test results, including excessive reassurance seeking and avoidance. An important finding was that in each of the key outcome variables at least one of these factors was a better predictor of reactions 3 months after the scan than the test result itself.

Applying cognitive-behavioural models to genetic testing for psychological disorders

We suggest that CB models of distress are likely to be useful in understanding and predicting reactions to predictive testing for psychological illness – both the CB model of health anxiety described above, and CB models of the other psychological disorders. The basic tenet of cognitive-behavioural models, that the individual's appraisal of a situation will determine their psychological response, is certainly applicable in this situation. Again, it is expected that certain general beliefs will be important in influencing responses to testing. For example, someone who believes that psychological illness is something deeply shameful will react with more distress to news of high risk than someone who does not see psychological illness as being particularly shameful. Specific beliefs about the condition in question will also be important in determining the extent of distress – beliefs about one's risk, the seriousness of the problem, potential treatment/prevention, and anticipated coping ability. For example, someone who believes that depression ruins every aspect of one's life and is untreatable will be more distressed after a high risk result than someone who believes that depression can fairly easily be controlled and treated. Someone who interprets their risk as being particularly high will be more anxious than someone who believes that they are at lower risk. After testing for HD (which, as a fully penetrant single gene disorder, gives relatively unambiguous test results) it has been found that there can be considerable individual differences in the way in which a high risk test result is interpreted and that this may be influenced by pre-test risk beliefs (e.g. Codori & Brandt, 1994). Pre-test beliefs would be expected to be still more influential in the interpretation of the results of testing for multifactorial conditions, since the implications of such results are more ambiguous.

Beliefs about risk, seriousness, coping and treatment/prevention regarding the condition will have developed over the person's life. These beliefs will be influenced by previous personal experience of psychological illness, seeing psychological disorder in family or friends and information in the mass media. For example, someone whose schizophrenic relative committed suicide will have a different view of schizophrenia than someone whose schizophrenic relative responded well to treatment. The ways in which other people reacted to their relative (e.g. the degree of sympathy and understanding, or avoidance and rejection) are also likely to affect the individual's beliefs about the condition. If the person has had a previous fairly mild episode of the condition in question they will be less distressed by an increased-risk result than if they were very severely affected. With regard to the mass media, there are frequent reports about different psychological conditions, with varying degrees of accuracy and understanding. It is clear that some conditions are portrayed in a more negative fashion than others, such as schizophrenia often being associated with violence.

Beliefs about genes will also be an important influence on the way in which the person interprets their result. For example, if someone has already had an episode of psychological illness and finds that they are at high genetic risk for that illness, they may feel diminished responsibility for the episode and blame themselves less. They may see their psychological problems as something that relates more to their family history than to them as an individual. An increased-risk result could therefore have positive implications for people's beliefs about themselves. Unfortunately if someone is already feeling depressed or has low self-esteem, it may be more likely that they will interpret

the result in a negative way and conclude (for example) that their genetic risk implies some more generalized intrinsic flaw.

Cognitive-behavioural models generally also focus on ways in which distress is maintained. In the case of genetic testing for psychological problems, there are various responses that cognitive-behavioural models predict will maintain or increase the person's distress. For example, some people may begin to pay greater attention to their psychological state in order to detect any symptoms of disorder. If the person already has a tendency to be anxious they are particularly likely to show an increased attention to threatening information such as possible psychological symptoms. Constantly checking for symptoms will keep the person focused on worries about having an increased risk and prevent them from finding ways of coping and getting on with the rest of their life. Furthermore, since most people at times experience mental phenomena such as intrusive thoughts, transient distress, lapses of concentration, memory problems and so on, it is likely that the person paying close attention to their psychological state will detect features that they could interpret as signs of impending psychological illness. This interpretation will cause distress and may increase psychological symptoms which they fear (e.g. difficultly concentrating), which could eventually lead to a vicious circle of misinterpretation and increased distress.

Another maladaptive reaction that may maintain distress is the attempt to suppress thoughts that the person thinks may be associated with disorder. This is likely to be counter-productive since there is evidence that thought suppression leads to an increase in the thought and increased distress (Trinder & Salkovskis, 1994). Furthermore, the patient may repeatedly attempt to seek reassurance about their mental state from friends and relatives, which may cause difficulties in these relationships. For people who are very anxious, any reassurance given is likely to have only a temporary anxiety-reducing effect and in the long-term may maintain the person's preoccupation with their genetic risk (Salkovskis & Warwick, 1986). Similarly, the person may request frequent consultations with health professionals about their symptoms (this has already been found in some people who receive a high-risk HD result; Wiggins et al., 1992); such behaviour will also maintain their focus on the problem and will probably provide only temporary reassurance. Avoidance behaviours are likely in people who are very distressed; for example, avoiding thinking, reading or hearing about the disease in question or avoiding situations that are reminders of the increased-risk results. Although avoidance is aimed at reducing distress it actually means that the person does not confront their fears and negative beliefs and they are prevented from leading a normal life. The person may also become fearful of negative psychological states and could attempt to suppress negative emotions or could start abusing substances that provide relief from these emotions. Both of these responses may have detrimental effects on psychological health in the long-term.

Some unhelpful reactions will be specific to the condition in question. For example, someone who learns that they are at risk for eating disorders may feel that it would therefore be a good idea to control their food intake more closely; this may have a counter-productive effect, by increasing preoccupation with food, encouraging inappropriate attitudes towards food and hence increasing their vulnerability to an eating disorder. With addictive disorders, the news that the person is at risk may have a "forbidden fruit" effect for the substance in question, making it appear more desirable

yet more guilt-inducing; this may increase a tendency towards self-restriction alternating with bingeing. Someone who is found to be vulnerable to anxiety disorders may begin to be concerned if they find themselves worrying; this may cause problems because it has been suggested that "worry about worry" is an aetiological factor in generalized anxiety disorder (e.g. Wells & Matthews, 1994). Someone at risk for obsessive-compulsive disorder may begin to develop negative attitudes towards repetitive or intrusive thoughts, which is likely to increase their risk for developing the disorder (Salkovskis, 1996). For someone who finds that they are vulnerable to depression, the first signs of low mood or sadness may elicit hopelessness and despair which wouldn't otherwise have occurred, because they interpret such symptoms as the beginning of mental illness. Thus it is clear that some people may react to news of increased-risk test result with behaviours that increase their risk for the disorder. Post-test psychological help should be given to help the individual avoid reacting in these ways.

Ways of coping with the test result

Research is needed into the ways in which people cope with the result from their genetic test. For example, there is evidence suggesting that one way in which some people may cope with a high-risk result from a health test is to "minimize" the risk itself or the seriousness of having the risk factor (Rimes, Salkovskis, & Shipman, submitted; Codori & Brandt, 1994; Croyle & Ditto, 1990). We found that women who were told they have low bone density rated low bone density as less serious than women who had high bone density, and showed significantly lower seriousness ratings after their result than beforehand. This minimization was *not* associated with fewer preventative behaviours. Codori and Brandt (1994) found that at 6 months after the test, gene carriers estimated their risk as much lower (60%) than was initially revealed at disclosure (>95%). Minimization may also occur in predictive genetic testing for other psychological disorders. The mechanisms behind minimization are not known, although it is possible, for example, that relatively optimistic seriousness beliefs are sometimes the result of selective comparison, e.g. the person telling themselves that their high risk result is not as serious as being at risk for certain other psychological disorders or as being at risk for certain *physical* disorders. In genetic testing for multifactorial conditions, the person who finds that they are at relatively high genetic risk may also be able to conclude that *overall* they are not at high risk because they are at low risk in terms of non-genetic factors. It is important to make the distinction between minimization, which may be an adaptive response, and complete denial, which may sometimes be associated with poor coping (Davey, 1993). The mechanisms of these and other reactions to genetic testing need to be investigated so that successful coping strategies can be encouraged and help can be given to people who use potentially maladaptive coping strategies.

Further issues: problems of reliability and validity of diagnosis and the provision of genetic information in current practice

Evaluation of the contribution of genetic factors to particular psychological disorders, both for the disorder in general and for particular individuals, requires the reliable and

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valid identification of those suffering from the problem in question. However, the criteria for diagnosing ''psychological disorders'' vary enormously in their reliability and validity, from the ''Axis II'' disorders (''Personality disorders'') which tend to have poor reliability and validity (Perry, 1992; Steiner, Tebes, Sledge, & Walker, 1995) through to the relatively more robust criteria for manic-depressive disorders. An alternative to the use of diagnostic interviewing would be the use of biological markers (e.g. the use of neurochemical challenge tests). However, Philibert, Egeland, Paul and Ginns (1997) point out that even in bipolar affective disorder, where the contribution of biological factors is relatively well established, biological markers of the disorder have not been identified. This means that researchers and clinicians rely exclusively on relatively unreliable categorical diagnoses based on clinical interview data. A further complication is that differential diagnosis often takes family history into account (DSM-IV; American Psychiatric Association, 1994, p. 355), which could lead to an overestimation of the contribution of genetic factors.

The identification of genetic influences on behaviour does not necessarily mean that psychological problems are best viewed as inherited diseases with a specific pathophysiology. Opinions vary on whether disease models are appropriate as a way of conceptualizing psychological problems. It is possible that mental health professionals may lose sight of the impact on their patients of their adoption of particular views concerning the nature of psychological problems. Some professionals and patients may regard the identification of genetic factors as indicating that the person's problem is purely biologically determined. Clinical experience suggests that, given a choice, patients generally prefer treatments that they believe deal with what they perceive to be causal factors rather than ''symptomatic'' approaches. The patient who firmly believes their anxiety is caused by genetic factors is likely to prefer an intervention that they believe will correct the ''cause'' of their problem rather than one which will change the way in which they react psychologically to potentially stressful situations. This belief could prevent some patients from accepting or engaging fully in well validated psychological treatments.

The present paper has considered the effects of genetic information in the context of genetic testing, with a view to considering how best to manage the likely consequences of such testing if it was to become technically feasible. However, many of these issues are also relevant to current practice, in terms of the way that clinicians describe the importance of genetic contributions to their psychological problem. This may be done in a general way by specifying that a particular disease is known to have a genetic basis, or genetic information may be elicited in the form of family pedigrees and then explained to the patient as indicating that their problem has a genetic basis. Those making such pronouncements clearly need to consider the likely impact of such suggestions on the patient's psychological well-being. There is an urgent need within mental health settings for research into the impact of providing patients with particular explanations for the aetiology of psychological problems.

Conclusions

There are many reasons to be concerned about the psychological and behavioural effects of genetic testing for psychological disorders. Such testing should initially be

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carried out in research settings so that the range of psychological responses to different types of testing can be monitored, both in the person tested and their family. This will inform the debate over the possibility of such testing being widely available. If it is shown that adverse psychological reactions are common or long-lasting, it may be decided that the costs of this testing outweigh the benefits. The intention to offer psychological help as part of genetic counselling should not be used to justify the availability of tests that can create much distress, unless it can be demonstrated that psychological interventions given to those tested do in fact help to reduce their distress and help them to cope with the result. Genetic counselling should also be evaluated with regard to its effect on patient understanding and decision-making.

In the consideration of the advisability and possible implementation of genetic testing for psychological disorders, there is a need for a theoretical basis for understanding the psychological issues involved in such testing. This could then be used to generate hypotheses for research concerning the type of variables that predict the range of psychological and behavioural responses to testing. Once factors determining different responses to testing have been identified, this will aid the development of interventions to prevent or reduce strong and persistent adverse reactions. It should also make it possible to identify people who are likely to react in particularly negative ways; these people should be given extra psychological help focused on their individual needs. If genetic testing for psychological problems does becomes available, everyone who receives a high-risk result should be offered psychological interventions that not only help them to cope with the distress caused by the test result but also educate them about the disorder in question, such as how to recognize the symptoms and when to seek help. Preventative interventions should be developed for those with a high-risk result in order to minimize their chances of developing the disorder or experiencing a worsening of an existing problem. It is important that a high-risk result does not become a self-fulfilling prophecy.

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