

Genetic discrimination and mental illness: a case report

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Abstract

With advances in genetic technology, there are increasing concerns about the way in which genetic information may be abused, particularly in people at increased genetic risk of developing certain disorders. In a recent case in Hong Kong, the court ruled that it was unlawful for the civil service to discriminate in employment, for the sake of public safety, against people with a family history of mental illness. The plaintiffs showed no signs of any mental health problems and no genetic testing was performed. This was the first case concerning genetic discrimination in common law jurisdictions, therefore the court's judgment has implications for how genetic discrimination cases may be considered in the future. The court considered it inappropriate to apply population statistics or lifetime risks to individuals while examining fitness for work. It recommended an individualised assessment of specific risks within the job, relative to other risks posed by that workplace.

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Introduction

Genetic discrimination is discrimination against an individual or his or her relatives because of *real or perceived* (emphasis added) differences from the ideal genome.¹ With a surge of interest in genetic research, the development of new technologies and completion of the sequencing of the human genome, we are now able to find out, through genetic testing, genetic information about not only the individual who took the test, but also about his or her family members. Genetic information clearly provides benefits: for example, in giving information about risk of future disease, disability and early death; and in enabling early detection and treatment of disorders. There is widespread concern, however, both at public policy level² and at an individual level^{3–5} about misuse of this information as grounds for discrimination, for example in employment, access to health care or access to insurance. People may be discouraged from obtaining genetic information that could bring health benefits to themselves and their families because of fear about the misuse of test results or inferences drawn from the fact that a test was sought. Genetic discrimination in the workplace has attracted particular attention recently.⁶ Many states in the United States have introduced legislation to protect

their citizens against genetic discrimination,⁷ and the White House has endorsed regulations against genetic discrimination in federal jobs.⁸

We report a case in which the discrimination was based on a “perceived” deviation from the ideal genome, when in fact no abnormal genes were identified. Because of concerns about public safety, asymptomatic individuals with no past history of mental disturbance were denied employment in the “disciplined forces” in Hong Kong, (members of the public service responsible for law enforcement or for save and rescue, for example the police, customs and excise officers, members of the fire service and ambulance service) on the basis of a history of schizophrenia in a first degree relative. The judgment of the court in this case outlines general principles and the line of reasoning to be followed when considering such a case. These principles are relevant for similar cases in the future.

Genetics of schizophrenia

There is no doubt that genetics is important in the aetiology of schizophrenia. Family studies⁹ have revealed that the relatives of affected individuals are at a higher risk of schizophrenia than the general population (about 1% worldwide), and the risk is a function of the degree of genetic relatedness to the proband. The highest risks, of 46% and 48%, are found in the offspring of two schizophrenic parents and the co-twins of affected identical twins respectively, and this declines to a rate of 2% for third degree relatives (for example cousins). Findings from twin studies and adoption studies¹⁰ similarly point to the importance of genetic influences in the aetiology of schizophrenia, while acknowledging that environmental factors also play a role. Schizophrenia appears to be a polygenic multifactorial disease. It has been estimated that about 70% of the variation in the liability to develop schizophrenia is accounted for by genes, with the remaining 30% of variation being explained by the environment.¹¹ Linkage and association studies have so far not clearly localised any chromosomal region or specific gene,¹² and the mode of inheritance remains unknown. Although a genetic test is available for some single gene disorders, for example, Huntington's disease, there is currently no genetic test for schizophrenia.

Facts of the case¹³

The plaintiffs were three young men who had applied for jobs in the Hong Kong civil service. K

and Y applied for jobs in the Fire Services Department (FSD) as an ambulance man and a fireman respectively. Both of them were rejected. W had been offered a job with the Customs and Excise Department (CED), but his employment was terminated after a medical examination that included obtaining information about serious illnesses in the applicant's family. In each of these cases, refusal or termination of employment was due to a history of mental illness, namely schizophrenia, in a parent. The plaintiffs, through the Equal Opportunities Commission, sued the Secretary of Justice for and on behalf of the Fire Services Department and Customs and Excise Department of Hong Kong. The three claims were heard together in the District Court of Hong Kong in September, 2000. Each of the three claims were begun under the Disability Discrimination Ordinance,¹⁴ claiming that the defendant had committed an act of discrimination in employment contrary to the part III of the ordinance which prohibits discrimination in employment against persons with a disability or persons with an associate with a disability.

Up till 1997, the disciplined forces in Hong Kong had always had the policy that first degree relatives of persons with mental disorder of a hereditary nature (for example schizophrenia and bipolar affective disorder) would be excluded from jobs in those departments.¹⁵ If candidates had a family history of such mental disorders, they would be declared unfit by the medical board examining them. When the Disability Discrimination Ordinance came into effect in December 1996, a Task Force on Mental Requirement of Disciplinary Forces issued revised guidelines to the Medical Examination Board, emphasising that there should not be discrimination against the mentally ill and that the policy of excluding people with mentally ill first degree relatives should be relaxed.¹⁶ It appears the defendants did not change their recruitment policy despite these revised guidelines.

ARGUMENTS FROM THE DEFENCE

The defence cited public safety as their grounds for denying employment to the plaintiffs. Anything that tends to increase the risk to the safety of fellow employees or members of the public is relevant to the plaintiffs' ability to carry out the inherent requirement of their respective employment. A child of a person with schizophrenia has a 13% risk of developing schizophrenia, compared to a one per cent risk in the general population.¹⁷ The mother of K and the mother of W suffer from schizophrenia, while Y's late father had a mental illness, which, at the time of his death, was diagnosed as schizophrenia. This was the reason for refusing or terminating each of the plaintiffs' employment. Under the Disability Discrimination Ordinance of Hong Kong, it is unlawful, subject to a number of statutory exceptions, to discriminate against a person with a disability or a person with an associate with a disability by refusing to offer that person employment. The defence relied on one of these statutory

exceptions: where the person with the disability (or with an associate with the disability) is unable to carry out the "inherent requirements of the particular employment" (section 12(2)). Safety to the public and fellow employees was cited as an inherent requirement of the jobs concerned. The defence suggested that the nature of the jobs and the duties of the respective departments put employees in a highly stressful situation, thus further increasing the risk of onset of schizophrenia. During the period of onset of schizophrenia, the individual may pose a risk to the safety of other employees and to the general public.

PLAINTIFFS' COUNTERARGUMENTS

There was some controversy about the actual diagnosis of Y's father, because he did not have typical clinical features of schizophrenia. The second author, one of the expert witnesses for the plaintiffs, examined the medical records of Y's father and suggested that he actually suffered from a delusional disorder. This revised diagnosis was accepted by the court. Delusional disorder is a rare disorder compared to schizophrenia, with a later age of onset. So far there is no evidence that it is hereditary.

There was no argument about the diagnosis of schizophrenia in the respective parents of K and W. As outlined earlier, genes undoubtedly play an important part in the aetiology of schizophrenia, but the mode of inheritance of familial schizophrenia is unknown. It is not possible to make a precise prediction of individual risks for schizophrenia because schizophrenia is not a single gene disorder. In fact, schizophrenia is likely to result from the combined effect of many genes and environmental factors. The figure of 13% risk of developing schizophrenia if one parent had the disorder (in contrast to a population risk of one per cent) can only be a starting point in the assessment of risk in any individual.

The plaintiffs had two world renowned psychiatric geneticists, Professor I I Gottesman and Professor P McGuffin as expert witnesses. They described two methods of predicting individual risk in vulnerable individuals.¹⁸ The "empirical risk prediction" takes into account the severity of illness in the sick parent and the psychological characteristics of the other parent; while the "multifactorial computerised risk model" takes into account other members of the pedigree in addition to the parent who is mentally ill, giving "credit" for healthy members and "debit" for every sick relative. Furthermore, the individual risk needs to be adjusted for the age of the person, since the risk gets lower as a person "survives" longer into the at-risk period without development of schizophrenia. With such adjustments, the risks of K and W were reduced to 5.4% (v 0.8% of a random male in the general population matched for age). In addition, the plaintiffs were each individually examined clinically. The psychiatric examination showed no psychiatric symptoms or prodromal symptoms, which could precede onset of schizophrenia by a

period of time. For this reason, the individual risk of developing schizophrenia in each plaintiff was reduced to well below 5%. There was no evidence, contrary to the defendant's suggestion, that the occupations of fireman, ambulance man, or customs officer increase the risk of developing schizophrenia.

Even if there is an elevated risk of developing schizophrenia, there should be a further step in quantifying the risk of threat to public safety. It is important to point out that public safety would only be threatened if the schizophrenic illness were acute in onset, therefore giving no time for detection of the mental disorder and no opportunity to take the necessary action which may include referral for medical attention, and a move to a less stressful job, as well as ongoing monitoring of and support for the patient. Empirical findings indicate that acute onset schizophrenia (developing over days or weeks) is in fact relatively rare.¹⁹ Possible adverse consequences of the onset of schizophrenia include two broad aspects: violent behaviour and a failure to perform a work duty. The risk of failure to perform a work duty is not clear since there is no previous research in this area in the context of the jobs in question. The defence cited studies examining the risk of violence in schizophrenia.²⁰⁻²² The consensus from the literature is that schizophrenia is associated with a slight excess of violence when compared to non-schizophrenia, and the violence is almost exclusively minor. Main contributors to the risk of violence are in fact those recognised in non-schizophrenic people, for example, past history of violence and substance abuse.²³ These risk factors were not present in the plaintiffs. In addition, the studies on dangerousness all relate to established diagnoses of schizophrenia whereas here we are only concerned with dangerousness at the onset of the illness. It would be reasonable to expect that the risk of violence is lower at the onset period. Taking all these considerations into account, the estimated risk of dangerousness in the plaintiffs was further reduced to 0.4%.

An absolute figure of 0.4% has little meaning unless compared to risks that are deemed acceptable in the specific job. The judge cited Gibson J of the Federal Court of Canada in Canada (Attorney General) v Thwaites (1994) FC 38,²⁴: "In any particular situation, one must determine when risks are significant and thus unacceptable by identifying the nature and quantum of other risks that are tolerated as acceptable in that particular work environment". The defendant's policy only excluded people with a family history of mental disorder in first degree relatives, not in second degree relatives. Second degree relatives have an average risk of 6% of developing schizophrenia. This is higher than the 5.4% risk estimated in K and W when adjusted for age. In addition, the FSD and CED do not require that onset of mental illness in family members be reported after a person has been recruited. The conclusion was that degrees of risk comparable to K's and W's individualised risks are already tolerated by the FSD and CED. Moreover, around

89% of all persons suffering from schizophrenia will have neither parent ill with schizophrenia. Therefore, the magnitude of risk faced by the FSD and CED would not be significantly diminished by discriminating against individuals with first degree relatives with schizophrenia.

COURT DECISION

The court ruled that discrimination against Y was unlawful since there was no evidence that delusional disorder, from which Y's late father suffered, was a hereditary disorder. Discrimination against K and W was also ruled unlawful since K's and W's genetic liability to develop schizophrenia, when weighed with the possible consequences if that risk occurred, did not present a real risk to safety at their places of employment. They were therefore judged to be able to carry out that inherent requirement of the job. At the invitation of the defence, the court considered how an employer might lawfully screen for vulnerability to schizophrenia in a job applicant. Based on the individual assessment of genetic risk undertaken for the plaintiffs, schizophrenia in any first degree relative of a job applicant, on its own, would not pose a real risk to the applicant. They should therefore not be excluded from employment in the disciplined forces. Further enquiry about risk is only warranted if the genetic liability is much higher than it is for a first degree relative, for example if there were more than one close relative with a history of schizophrenia. In any case, an individual assessment of the applicant's genetic risk must be made, with an examination for prodromal signs, taking into account the subtype of schizophrenia in the relative and the age of the applicant. The nature and magnitude of the risk involved should be examined in order to assess whether it posed a real risk in the job in question, relative to other risks tolerated in that workplace. The plaintiffs were each awarded damages between Hong Kong \$775,000 (about £68,000) and over \$1 million (about £88,000), plus costs.

Discussion

Recent advances in genetic technologies and the possibility of identifying a wide range of genetic abnormalities have raised much concern about genetic discrimination. In this case, no genetic testing was performed, and no abnormal genotype had been identified in the plaintiffs. In fact, no genetic testing is possible for schizophrenia since the precise mechanism by which schizophrenia is inherited is unknown, and the abnormal genes that confer vulnerability to schizophrenia have not yet been identified. Moreover, even if the molecular genetic basis of schizophrenia was better understood, it is unlikely that individual risk prediction would ever be better than about 50% since monozygotic twins are discordant for schizophrenia about 50% of the time.²¹ The discrimination in employment was the result of "perceived" (rather than real) differences from the ideal genome because of a history of schizophrenia in a first degree relative. Having said that, this important

case illustrates some important general principles in considering when unlawful genetic discrimination occurs in employment, whether the discrimination is based on perceived (when genetic status was inferred from a family history) or real differences (when genetic testing had revealed an abnormal gene) from the ideal genome. First, there should be an individualised estimation of the risk of the person developing the disorder. This individualised estimation should take into account the role of environmental factors, the age of the person and his or her current health status. Equally important is a consideration of the specific nature of the disability, and whether there is a risk that the individual would, as a result of the disability, fail to carry out an inherent requirement of the job in question. Furthermore, we need to ascertain the magnitude of this risk and the seriousness of the consequences if this risk were to be realised, taking into account the possibility of preventive measures that could be taken to avoid harm. Whether the increased risk is significant is determined by comparing it with other risks that the employer is willing to accept. Clearly, public safety is an important legitimate concern in recruiting staff for the disciplined forces, especially as some of them may have access to firearms. The court, by outlining as above, a process of pre-employment screening for individuals who are genetically liable to develop schizophrenia, recognised that public safety might override an individual's right to freedom from discrimination in employment in certain specified situations. The general principles and line of reasoning used by the court set a standard for such risk assessment.

The case was considered in a very "clinical" manner, citing figures from empirical studies with calculations of individualised risks based on clinical data. It is important, however, to consider the social and cultural context within which this case arose. On the 1st of November 1997, after the job applications of Y and W had been refused and while K's application was still pending, a tragic event occurred at a local police station. A police officer, acting under a delusion that a detainee, under his guard, was a ghost and about to attack him, shot the detainee with his service revolver, killing him. The officer was afterwards diagnosed as schizophrenic. A sibling of this police officer had been diagnosed as schizophrenic six months previously. Prior to the tragic incident, there had been no warning signs at work that his mental state was worsening. The decisions to reject the plaintiffs were made when this piece of news was fresh in the minds of those concerned and among the people of Hong Kong. Ironically, the recruitment policy of the police force would not have prevented the recruitment of the police officer in this case. The officer's brother became ill after the officer joined the force, and there was no requirement to report development of mental illness in a family member after a person was in employment.

Taking a broader view, stigmatisation of people with mental disorders and their families is

widespread.²⁵⁻²⁷ The general public often perceives people with schizophrenia to be unpredictable and dangerous.²⁸ This perception is not supported by the empirical evidence arising from the examination of the risk of serious violence in people with schizophrenia. There is a need for wide public education and debate on this issue. Taylor and Gunn,²⁹ distinguished forensic psychiatrists from the UK, have stated: "Psychiatrists might help themselves and their patients by taking an information-based but higher profile in public and political debate to counter popular and stigmatising mythologies about people with mental disorder. People with mental illness account for a *minute* (emphasis added) amount of risk to the general public" Similarly, Wallace, *et al* from Australia concluded from their study on serious criminal offending and mental disorder that the risk of a serious crime being committed by someone with a major mental illness is small and "does not justify subjecting them, as a group, to either increased institutional containment or greater coercion".³⁰ More specific examinations of attitudes towards mental illness in Chinese communities suggest that these communities are less accepting of mentally ill people, and that stigma is often attached to the family as a whole.³¹ In a detailed examination of mental health care in China, Pearson wrote: "There is widespread belief that mental illness is a punishment for the ancestors' misdeeds visited on the present generation, effectively shaming several generations of the family simultaneously. The 'taint' associated with mental illness is so strong that it extends beyond the affected person, for instance with regard to the issue of marriage".³² The burden of shame and guilt carried by the family intensifies the stigma, and often leads to efforts to concealing mental illness in a family member. In many countries recently, campaigns have been launched to combat stigmatisation of mental illnesses.³³ This case, which was widely reported locally, sends a clear and unambiguous message to the public that discrimination against people with psychiatric disorders and against their families is unlawful, unnecessary and inappropriate.

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