Ethics and psychiatric genetics: is it ethical to test for ‘depression genes’?

Only one fact is certain about the future of genetic research: it will continue to raise ethical challenges for scientists, research participants, clinicians and patients (Faraone et al, 1999). Ethical issues are of concern in all branches of medicine and genetics, but they are of particular concern in the field of psychiatric genetics. This is because of the special nature of psychiatry, and its position at the intersection of the disciplines of psychology, sociology and medicine. The concern is also related to the perceived subject matter of psychiatry: the core thoughts, feelings and emotions by which we define ourselves as human beings. Many are perturbed by the idea that modifying genes could modify these features. By ‘interfering’ with our genetic heritage, it is perceived that our essential humanity is coming under threat, and the possible outcomes of this interference are worryingly unknown.

The purpose of scientific endeavour is to create knowledge. Knowledge, such as that generated by the Human Genome Project, is in itself neutral from a moral and ethical perspective; however, the potential applications of the information generated by such projects are not ethically neutral. Historical precedent compounds public concern: in the first part of the 20th century, eugenics — the idea that public policy could clean up the gene pool — was promoted by scientists in many developed countries. In the hands of the Nazis, these ideas led to murder and forced sterilisation. The historical misuse of genetic data is a warning to contemporary scientists and clinical geneticists. Although the clinical application of genetic data might save lives and decrease disability, its political application could be devastating.

The search for ‘depression genes’

A well-staffed, highly-resourced, multicentred study is now in progress, aimed at identifying the ‘susceptibility genes’ that underlie unipolar depression. The lead site outside the USA for this extensive project is the Maudsley Hospital, in London. Given its resources and experienced personnel, it is likely that this well-funded research project will identify the susceptibility genes for what is a common and disabling condition (Wallace et al, 2002). This discovery, in turn, could conceivably lead to the development of a ‘diagnostic kit’ whereby a general practitioner or psychiatrist would be able to estimate an individual patient’s genetic liability to depression, even prior to the onset of the disorder (pre-symptomatic genetic testing).

What are the ethical implications of this type of research, and how will we address the ethical issues involved in pre-symptomatic testing for common psychiatric disorders such as depression? Specifically, how do we decide whether pre-symptomatic genetic testing for common psychiatric disorders such as depression, is ethical?

Ethical models

Ethics takes into account the interests of people other than ourselves. The search for a rational understanding of the principles of human conduct began with the ancient Greeks, and can be traced from Socrates and his successors, Plato and Aristotle, through Roman and medieval times, to the ethical philosophies of the Utilitarians and the German philosopher Immanuel Kant (Rowe, 1996). These two models, Kantian and utilitarian, have had a major impact on medical ethics.

Utilitarianism

There are reasons of a moral sort for arguing in favour of, or against, the use of testing for an illness such as depression before its symptoms actually appear. The utilitarians (Jeremy Bentham and John Stuart Mill) saw the consequences of an action (such as pre-symptomatic genetic testing) as the criterion of good or bad, right or wrong. Utilitarianism thus is essentially a consequentialist theory, with the rightness of an action not intrinsic but dependent on its consequences. The greatest happiness of the greatest number is the consequence desired (Thompson, 2001). This consequentialist view can, however, be seriously criticised: the philosophy may not account for our intuitions about justice and truth-telling and – most importantly – it is very difficult to predict the actual consequences of any action, especially one such as pre-symptomatic testing, which might equally well lead to suicide and reckless behaviour rather than more positive and adaptive coping strategies.

The views of Immanuel Kant have been revised in recent years in opposition to the long tradition of utilitarian thought (Scheewind, 1996). It can be argued that no utilitarian account of justice can adequately incorporate our common-sense convictions as can the Kantian approach, with its emphasis on respect for the individual and that the right is prior to the good.

Immanuel Kant

Immanuel Kant (1724–1804) is commonly regarded as the most outstanding figure to have emerged in philosophy since antiquity (Magee, 1997). Having been awakened from his ‘dogmatic slumbers’ by the Scottish philosopher, David Hume, Kant’s ethical system, as set out in his
Any doctrine such as utilitarianism that gives morality a reason outside itself, such as commonly shared moral beliefs or preferences, Kant has nothing to do with, rather all moral concepts must have their origin wholly a priori in reason not in consequences. Kant was firmly opposed to the idea that the morality of an action is determined by its outcome and felt that actions are right or wrong regardless of their consequences. Kant, who according to Russell (1945) led a life that was exemplary and academic, believed that morality, like science, is fundamentally founded on reason. More importantly, Kant also offered a principle called the ‘formula of the end in itself’ which is not abstract and is easy to apply to human dilemmas (Thomson, 2001). Kant states that we should never treat other people ‘simply as a means’, but we must always treat every person ‘as an end in himself’. We should respect others as rational persons with aims and purposes of their own. We should also help other people achieve some of their aims and (of course) we should not harm them. We must not deceive others, because this reduces their choice of achieving their aims and objectives and also treats them simply ‘as a means’. This has specific implications for the process of pre-symptomatic testing for the susceptibility genes believed to underlie unipolar depression.

The use of pre-symptomatic testing can be seen as consistent with Kant’s ethical view of human beings as rational beings with aims and purposes of their own. Pre-symptomatic genetic testing for ‘depression genes’ could potentially help people become more autonomous and so help them achieve their aims. Although Kant asserts that we should strive to help others, his formula also implies, in a somewhat stronger form, that we should never harm others. How we minimise this risk is pivotal in addressing ethical concerns regarding pre-symptomatic testing – and indeed ethical concerns impinging on genetic research in general. By providing patients with verbal and written, easily understood, comprehensive information regarding genetic testing prior to seeking their consent, we resolve an important ethical dilemma, because we enhance the patients’ choice and inform the patients’ own aims and ends. We avoid the harm of deception and we treat patients as an ‘end in themselves’ not simply as a means. By providing patients with comprehensive information prior to pre-symptomatic testing, we are going some distance in meeting Kant’s criteria for ethical action.

Pre-test counselling and informed consent

Kant’s emphasis on human freedom and dignity could be served by the wide availability of pre-symptomatic testing for psychiatric disorders such as depression, because it would enable the individual to respond if a test result indicated a high genetic loading for a particular disorder. Depressive disorder can lead to significant loss of dignity and self-esteem, and can cause significant suffering to the individual; it also imposes a major burden on society. By enabling an individual to take steps to decrease the likelihood of an illness episode, pre-symptomatic testing could enhance human dignity, in keeping with the Kantian ethical stance.

By adhering to a transparent procedure for obtaining informed consent, we go some way towards the resolution of the moral dilemma concerning genetic testing. Obtaining informed consent through pre-test counselling is consistent with Kantian logic, because the process avoids deception, enhances the patients’ autonomy and increases their ability to engage in authentic choice. By informing the patient in advance of every aspect of the procedure involved in pre-symptomatic testing, we are treating the individual’s welfare as an end, not simply as a means. When fully informed, the individual is more able to choose (Thomson, 2001). This is consistent with the Kantian imperative to allow individuals to act in accordance with their own maxims, and is in keeping with Kant’s ‘formula of the end in itself’. Such informed consent is the cornerstone of ethical research and practice, allowing individuals the opportunity to dissent and act according to their own values and ends (Faraone et al, 1999).

Conclusion

Is pre-symptomatic genetic testing ethical? Yes, it can be – provided that we implement the safeguard of comprehensive pre-test counselling, which in turn leads to informed written consent. This safeguard is consistent with a Kantian respect for human autonomy. This respect for human dignity is especially relevant to patients suffering from psychiatric disorder.

Declaration of interest

None.

References


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