Ethical issues in genetic research on depression

The evidence of genetic roots of depression

In 2003 the *New York Times* wrote that researchers had found a gene that may help explain why some people develop depression as a response to stressors and why other people do not. The researchers argued that the gene known as 5-HTT contains the code to produce a protein that regulates the level of the neurotransmitter serotonin. The researchers found that people with mutations in the gene were more likely to develop depression as a result of stressors - that is, they were genetically vulnerable and more likely to react to stressors by manifesting symptoms of depression. According to the researchers the gene could thus predict depression, but it is too early to use 5-HTT as a diagnostic test. Before this could happen more research should be done so that other genes that may play a role in vulnerability to depression could also be identified.

Ethical issues are a concern in genetic research – especially in the area of psychiatry because it deals with some of the most important areas of human functioning: emotions, thoughts and feelings. Psychiatry is a branch of medicine where values, science and clinical judgement are interwoven. This is because diagnosis involves judgements about people and their *self* which could challenge not only people’s self-understanding but also other people’s understanding of an individual. In other words, genetic diagnosis may lead to labeling, stigmatization, and even self-fulfilling prophecies.

When it comes to research on the possible link between genes and psychiatric disorders there are serious ethical issues because it is not yet well known how specific genes are linked to disorders, and it is also not known how genes and environmental factors interact. A person may be genetically predisposed – or vulnerable – to a specific disorder, but it may well be that the person will never develop the disorder. This is illustrated in the *diathesis-stress model* which assumes that genetic vulnerability must be triggered by environmental factors to be expressed.

Generating knowledge via genetic research –what to do with it?

The purpose of scientific research is to produce knowledge. In the case of genetic research the aim is to generate knowledge about the role of specific genes. Knowledge about the 20,000 genes in humans was obtained as a result of the Human Genome Project, but researchers are far from being able to determine the specific role of all genes. Therefore, one should be careful about making definitive conclusions in genetic research at this point. It is important to remember that the vast majority of research into the role of genes on behaviour is correlational in nature - causation has not yet been established.
According to Wallace (2004) it can be argued that it is not sure that a project like the Human Genome Project is ethically neutral. Historically, the idea of eugenics - that is, the study of good genes and bad genes has been a source of discrimination. In the case of Nazi Germany, eugenic theory led to the extermination of those suffering from mental illnesses. The misuse of ethically sensible data in Nazi Germany is a warning to contemporary scientists that although scientists work to save lives and decrease suffering, the political application of genetic knowledge could be devastating. Today it is well-known that a psychiatric diagnosis is often a social stigma that is difficult to erase; so if genetic testing would become the norm, it might be necessary to start public education to reduce stigmatization of patients.

Wallace illustrates this with reference to an ongoing study at the Maudsley Hospital in London. The aim of the study is to identify the genes that may underlie unipolar depression. According to Wallace it seems likely that a well-funded research project like this one may identify genes that could play a role in the development of depression. If this is the case, it could perhaps lead to the creation of a diagnostic tool that enables clinicians to estimate an individual patient’s susceptibility to depression even before the onset of the first symptom. This raises ethical implications such as whether pre-symptomatic testing should be done at all and whether it is ethical to test for a psychiatric disorder which may or may not develop.

5-HTT genetic test of depression- is it ethical?

Ethics deals with how researchers the respect the rights of the individual and still make scientific progress. According to the philosopher Immanuel Kant (1724-1804) ethics should be based on the idea of never treating human beings as subjects, or the means to achieve something. This means that scientists should not harm or deceive human participants in research and that all research should be based on informed consent. This includes research into genetic testing for depression. It has been suggested that pre-testing could eventually help people to prevent onset of depression or as a tool of diagnosis.

According to Newson (2009) genetic testing for depression requires a serious reconsideration of ethical issues in psychiatric diagnosis. First of all, it can be questioned whether such a test should be mandatory if there is depression in the family. It is also relevant to ask if a genetic test for depression in children could lead to problems for the persons in question instead of helping them. This could for example be the case if people after a genetic test learn that they have a genetic vulnerability for developing depression. According to Newson (2009) it could also be a problem if a young couple who wants children are tested and find out that their child is at risk for developing depression. Newson warns that screening programmes are expensive and not likely to be introduced at this point because of lack of knowledge of the interaction between
genes and the environment. It is also very difficult to have any clear prediction of onset of depression or how severe the condition would be. Newson also warns against genetic testing of children as this could influence the parent-child relationship and the child’s developing sense of self.

There are several reasons for being cautious when it comes to genetic testing of a psychiatric disorder like depression. For example, the 5-HTT gene has been linked to depression but so far screening of the 5-HTT gene has only revealed vulnerability. The 5-HTT gene is a measure of risk rather than certainty. Newson argues that it is not likely that the 5-HTT gene is the only reason for developing depression so a clear cause and effect relationship between genes and depression cannot be established at this point. However, genetic testing could reveal a possible risk for developing depression and the individual would then have to deal psychologically and socially with that information.

Questions to consider

1. Summarize what we know about the role of the 5-HTT gene in depression.
2. What is meant by "vulnerability?" Are there social or cultural reasons that someone could be vulnerable to depression? Cognitive reasons?
3. Outline the ethical concerns of genetic pre-testing for mental health disorders? Where do you stand on the issue?

References

