Genetic testing and insurance

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Genetic testing and insurance is a topic surrounded by considerable publicity, even controversy. Yet it is not new; more than 50 years ago R. A. Fisher, the distinguished geneticist and founder of modern statistics, spoke to a meeting of the insurance companies on the subject, and predicted that one day it would be possible to use genetic markers in assessing risks for insurance purposes [1]. That day has now come, and we have to face up to the difficult issues that Fisher had been able to contemplate as purely abstract problems.

- What is meant by genetic testing?
- Why is it different from other forms of testing and why is that important to the insurance profession?
- What ethical problems accompany its use?
- If it is to be used, what should and what should not be done?

The nature of genetic tests

The long chain of the DNA molecule in which the sequence of components determines the structure of proteins and thus the normal or abnormal functioning of all body processes, can be split into short stretches. Detailed studies of these segments have shown that harmless inherited variations—polymorphisms—occur at frequent intervals along the DNA chain, and that they can be used as markers for important disease-controlling genes located nearby. These DNA markers probably exist in and around every disease gene. They have been used to construct maps of the chromosomes, the structures on which the genes are arranged in linear order. Many thousands of such markers have already been isolated, and as more genes are found they also can be used as landmarks for neighbouring genes [2,3].

Special relevance of genetic testing

How does this new genetic testing differ in its consequences from other types of test used in medicine and by the insurance profession? The difference does not lie in any unique property of DNA analysis but in a combination of factors which include the following:

- **Independence of age.** The test result will be essentially the same at any point throughout life from conception to old age, since the genes themselves remain largely unaltered despite changes in their end products.
- **Independence of clinical state.** In most cases the test result will be the same whether a person has the disorder now or will develop it in 50 years time, whether it is mild or severe, or whether in some instances overt disease will never develop at all.
- **Independence of tissue.** Genes are present in all body cells, regardless of whether they are functioning or not. Thus the gene for a serious brain disease can be detected in the cells obtained from a blood or mouthwash sample, making it possible to test for diseases for which this had previously not been possible.
- **Stability and small scale of sample.** A single blood spot or mouthwash can provide enough cells for many tests, and the sample can remain usable for many years, thus raising the possibility of using (or misusing) samples originally taken for other reasons.

The power of genetic testing is thus not in doubt, but why should this be of special relevance to the insurance profession?

Genetic maps

The abundance of genetic markers has already resulted in the construction of a well developed genetic map of the human chromosomes, so it is likely that in the near future the genes for most serious inherited disorders will be mapped and isolated. At the time of the August 1991 Gene Mapping Workshop in London [4] only around 3,000 of the estimated 50,000 genes thought to be present in man had so far been recognised in terms of a definable inherited characteristic or disease, but about 1,700 of these have already been mapped in detail, including the serious disorders shown in Table 1. Genetic tests for all these disorders either already exist or are potentially available, accounting for a large body of serious chronic disease.

Susceptibility to disease

Of even greater importance from the insurance viewpoint is the group of common diseases to which we are all susceptible to a greater or lesser degree, such as those shown in Table 2. It has been known for many years that these disorders have a familial component, and insurance companies have recognised this by asking questions about illnesses of parents. The emerging

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Table 1. Examples of major inherited disorders where the gene has been mapped or isolated, allowing accurate genetic testing

| Disorder                                | Main effects                                                                 |
|-----------------------------------------|-----------------------------------------------------------------------------|
| Muscular dystrophies (Duchenne and other forms) | Progressive muscle weakness and disability; early death                      |
| Cystic fibrosis                         | Severe respiratory and digestive disease; early death frequent               |
| Huntington’s disease                    | Progressive involuntary movements; dementia; fatal course                     |
| Polycystic kidney disease               | Renal failure in adult life                                                  |
| Marfan syndrome                         | Excessive growth; early sudden death                                         |
| Familial polyposis of colon             | Early and multiple bowel cancer                                              |
| Retinitis pigmentosa (some forms)       | Progressive blindness                                                       |
| Neurofibromatosis                       | Skin and nerve tumours                                                      |

Table 2. Common disorders showing important gene susceptibility

| Disorder                              | Susceptibility gene(s) identified                        |
|---------------------------------------|---------------------------------------------------------|
| Early coronary heart disease          | Gene isolated for familial hypercholesterolaemia        |
| Breast cancer (early familial)        | Chromosome 17 marker                                    |
| Asthma (allergic form)                | Chromosome 11 marker                                    |
| Bowel cancer                          | Chromosome 5 gene involved in many tumours              |
| Schizophrenia                         | Under active study; no undisputed gene yet identified    |
| Manic depressive illness              |                                                         |
| Alzheimer’s disease                   | Chromosome 21 gene involved in some familial cases      |

gene map can now identify specific genetic components that are involved in susceptibility to disease. Everyone possesses such susceptibilities, but which ones? To know this in advance may help in avoiding harmful environmental factors (though this is debatable), but is it helpful in relation to insurance? Would there be anyone left to insure if such testing were to become widespread?

Problems associated with genetic testing

Some problems relevant to the insurance profession have already arisen and there are others that may arise in the future. A good example is Huntington’s disease (HD), a serious, fatal brain disorder of later life which causes progressive mental and physical disability over a 15–20 year period [5]. Although the gene has not yet been isolated, some close markers have been used in predictive tests for the past 5 years, with careful international co-ordination in their application. My own unit has handled more than 200 requests for such testing [6].

- Should individuals and their family doctors be obliged to disclose whether they have had a genetic test for HD, and if so, its results? Should such results form part of a person’s medical record? Should those who have been given a low risk, ‘normal’ result be able to use it to obtain insurance that would otherwise be denied them? These situations are already occurring, as shown by the example in Fig. 1. The person concerned here has given consent for the release of the information, but what does this imply? What was actually explained? Does this go against the principle of free choice without pressure or coercion? This principle is strongly emphasised by published international guidelines on predictive testing for HD [7].

- In our HD prediction series we have had no fewer than 28 requests for testing children for this late-onset ‘adult’ disease. We have refused to do such tests, because currently there is no treatment that can alter the course of the disease and because testing a child would remove that individual’s free choice when an adult [8]. But if it were done, would the individual have the right to insurance, or to legal redress against those who did the test?

These two specific situations for genetic testing for a specific disease show how serious are the issues involved; additional general issues arise for many other genetic disorders:

- Who will decide which diseases are serious enough to be tested in this way for insurance purposes?
Dear

We have received an application from your patient M . . . . . . requesting private medical insurance. In order that we may proceed with the application, we would be grateful if you could provide us with the results of the blood tests taken recently regarding the hereditary disease Huntington’s Chorea.

We have been given permission by M . . . . . . for us to request this information and he is aware that any fee which may be charged is not recoverable from . . . . .

We look forward to hearing from you.

Yours sincerely

Policy Administration Manager.

Fig. 1. Example of a recent request for access to genetic testing results in relation to insurance with identifying details removed to preserve confidentiality.

- Will testing be, as at present, through National Health Service based genetics units with full genetic counselling, or through commercial laboratories without such support?

These issues already demand an answer. But the finding of susceptibility genes for common cancers, heart disease and mental disorders promises to make this a more general problem affecting everyone, not just those with a rare disorder in their family. Any large and well documented family will contain individuals with such disorders and might therefore be considered to provide valid grounds for genetic testing of other family members. Will it be feasible to undertake genetic testing on the whole population and ultimately will there be anyone left who is insurable?

Ethical considerations

The ethical and practical issues relating to genetic testing and insurance have already been the subject of discussion in different countries. A questionnaire sent to medical geneticists and ethicists in 19 countries found many respondents with strongly expressed views [9]; the questions were in relation to employment but are probably relevant to insurance issues generally.

Wertz and Fletcher [9] found that people’s distrust of insurance companies was such that 40% of respondents thought that the companies should have no access at all, even with the worker’s consent. Very few (4%) thought that workers would benefit in any way from an insurance company knowing their test results. On the other hand, 30% thought that the information would be misused to the worker’s detriment.

The same authors quote a previous survey of employers about the future use of genetic testing, and it is relevant to note that insurance would be the first point of application of these tests:

‘An OTA survey of 12 companies interested in developing genetic screening tests showed nine thought employers are likely to use genetic tests to exclude workers from occupational hazards by the year 2000, and five thought that employers would use genetic tests to screen job applicants (US Congress, Office of Technology Assessment, 1988). They did not expect occupational screening to occur immediately however. Most thought that the first applications (by 1990) would occur in the insurance industry.’

The subject is also mentioned prominently in a report from the Health Council of the Netherlands, Heredity, Health and Society, dated late 1989 and recently made available in English [10]:

‘We find it unacceptable that people affected from birth with a genetic predisposition should be faced with additional social obstacles, and that their relatives should also be at a disadvantage in this way. It is felt that the suspicion that fear of insurance problems may deter some individuals from genetic testing is well-founded; in an atmosphere of growing uncertainty, genetic testing could be perceived as threatening. At the same time, however, we recognise that insurers are entitled to protect themselves against exploitation by persons with prior knowledge of their own risks, for example of developing a serious hereditary disease in the near future.’

This report is also clear as to the action to be recommended:

‘To avoid unacceptable consequences for insurance clients while minimising the risks to insurers of self-selection among clients, we advocate a ban on genetic testing in this situation, as well as restrictions on the requirement to disclose information from previous genetic tests. Further investigation of the European legal context is necessary.’

Suggestions

Having painted what may seem to be an alarming (or even alarmist) picture, can I offer any suggestions as to how to cope rationally with this topic? As a clinical geneticist and physician without expertise in the insurance field, I feel that the term ‘recommendations’ is too definitive, but I do have both specific and general suggestions which do not, as far as I know, contradict what is already existing policy and which might help to
avoid trouble in the immediate and longer term future.

At present we have a narrow window of opportunity, and I am not aware of any genetic tests being done or used for insurance purposes except in isolated instances. This is in part because most of the diseases involved are rare, tests are available only in specific research or medical centres, and most people are still unaware of the implications.

This situation will not persist, and I totally agree with the statement made by Baroness Warnock at the recent Human Gene Mapping Meeting, that this and related issues should be debated and resolved before widespread piecemeal applications of genetic testing take place.

My personal suggestions include the following (I am not speaking on behalf of any professional body here):

- There should be a moratorium on the use of genetic testing in relation to insurance until all concerned are much clearer as to whether or how it should be used. This should not cause immediate problems, as it is unlikely that any company has yet made a positive decision to use the results of genetic testing. There is a good precedent for this since there was a voluntary moratorium for several years in America on the development of molecular genetic tests while laboratory safety issues were being resolved. Such a moratorium would also help reassure public opinion on what has already become a highly charged issue in the public mind and in the media. Insurance companies would be in danger of finding themselves, unjustifiably, being judged along with authoritarian governments, employers, eugenicists and unscrupulous scientists, all considered (rightly or wrongly) as planning to make harmful use of the new genetic techniques. A few people might be adversely affected by such a moratorium, notably those with a family history of genetic disease who have themselves obtained a ‘normal’ result from genetic testing, but these would be few in comparison with the many who could be harmed by the rapid and uncoordinated application of such testing.

- Urgent discussion is needed between the insurance profession and the various groups involved in genetic testing: clinical geneticists and other clinicians involved with families with genetic disorders; laboratory scientists concerned with carrying out the tests and with new research developments; legal experts and ethicists; and government health departments. Some working parties have been established in the UK, while a considerable amount of information is already available from other countries. If such discussions begin now, it should be easier to reach a consensus than when entrenched positions have already been taken up. But it is not only professionals who need to be involved: public opinion in general needs to be taken into account, and the views of the lay members of the various genetic disease societies will be especially valuable.

- Guidelines need to be issued, but only when as clear an agreement as possible has been reached. It may be that the insurance profession proves to be so unanimous on this topic that these guidelines can be voluntary, but it is possible that some legislative framework will be needed, at least to set the limits of what is permissible. The legislation in Britain on research using human embryos shows that this, while difficult to achieve, can be beneficial to all concerned.

It should be borne in mind, however, that there are groups who have a vested interest in promoting the insurance-related use of genetic testing. I do not believe that the insurance profession is itself among these, but they could include biotechnology companies marketing the tests (for whom as wide a use as possible is a clear source of income), employers (who have an interest in excluding the potentially unhealthy), as well as family members who have already obtained a normal result and for whom there is an understandable sympathy.

At this stage, careful discussion and planning can ensure that the powerful new tools of genetics can be made useful servants for our benefit rather than become weapons of control and restriction. It is an issue that the insurance and medical-scientific professions will have to solve for the benefit of society as a whole as well as for each individual. For a short while only, the choice is still ours to determine.

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