The new genetics

Genetic testing and public policy

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This is the last of four articles discussing the broader implications of advances in genetics

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BMJ 1998;316:852-6

Summary points

The genetic components of many diseases are responsible for the predictive limitations of genetic tests

The validity and benefits of predictive genetic tests need to be established before these tests enter clinical use

Adverse social consequences of genetic tests, including discrimination and possible breaches of confidentiality, are barriers to testing; policies to minimise them need to be developed before testing will be widely accepted

Laboratories performing genetic tests require special quality assurance procedures. Further assurance of the quality of pretest and post-test education and counselling is also needed

Government policies are needed to assure the safe and effective use of genetic tests

The increasing rate of discovery of genes related to disease and the development of tests for them has fostered the idea that healthy people will be able to prevent future disease by undergoing genetic testing. The genetics of many diseases are such that tests have only a limited ability to predict the clinical outcome accurately. Nevertheless, the benefits of some predictive genetic tests can be substantial, such as screening newborns for phenylketonuria and sickle cell anemia and testing of older children at risk of familial medullary thyroid carcinoma and multiple endocrine neoplasia type 2a.[1] The fact remains that relatively few interventions have yet been devised to improve the outcome of most mendelian disorders.[2] When no treatments are available, genetic testing can be used to avoid the conception or birth of affected offspring. Carrier screening in Sardinia, Cyprus, and elsewhere in the Mediterranean has led to an appreciable reduction in the birth of infants with thalassaemia through the use of prenatal diagnosis in couples at high risk and their selective termination of affected fetuses.[3]

Genetic testing (box), including prenatal testing, also carries the risks of inducing psychological sequelae[4] and of making individuals vulnerable to discrimination and diminishing their privacy. Additional benefits of testing in refining clinical diagnosis and tailoring treatent may be in the offing,[5] but these remain to be shown.

Government involvement

Both the American and British governments have recognised at least some of these problems, but solutions have been slow in coming. The United States started earlier to create a structure to consider the problems, but at present no federal committee is dedicated to addressing issues of genetic testing (box). In its final report, the Task Force on Genetic Testing reviewed many of the problems of genetic testing and laid out specific recommendations[6]; the Secretary of Health and Human Services is considering how they should be implemented. The major stakeholders in genetic testing were represented on the task force.

In Britain, in response to the House of Commons Select Committee on Science and Technology,[7-9] the Conservative government set up two committees (box). Both committees contain clinical geneticists, other professionals concerned with genetic applications, media representatives, and consumers. Each committee has now addressed one issue in genetic testing.

Predicting genetic risks

Without sufficient data, there is no assurance that genetic tests will predict disease accurately. Although the quality of test performance is a factor, the genetics of the disorder often explains most of the difficulty. Variable expressivity, incomplete penetrance, and genetic heterogeneity all reduce the ability of genetic tests to predict future disease accurately, even when single genes have a prominent role (box). For many common disorders, including insulin dependent diabetes, hypertension, and schizophrenia, it seems likely that in the vast majority of cases, no single gene will be prominent but multiple genes will be implicated. However, different combinations of alleles at multiple loci and environmental factors will each be capable of increasing the risk of disease. Testing for any one of the possible combinations, which is not yet possible, will account for only a small proportion of patients. Unless a test detects most of the necessary alleles, it will have low predictive value.

Despite these limitations, exaggerated claims are made for genetic testing,[21] and providers and the public are given incomplete and sometimes misleading information about tests (B Wilfond, unpublished data).[6 22]

In the United States, the Task Force on Genetic Testing recommends requiring organisations developing new genetic tests to submit protocols for establishing the clinical validity (including sensitivity and positive predictive value) and utility of the tests to institutional review boards,[6] equivalent to local research ethics committees in the United Kingdom. Once data are collected, the task force calls for review of the data by an independent body including consumer representatives. The task force recommends using the results of review to consider whether the test should be introduced into practice and become the "standard of care." The Food and Drug Administration will perform the review for genetic tests marketed as tangible products, such as kits. For genetic tests marketed as services, as many genetic tests are, the Food and Drug Administra-

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A person's genetic test results may have bearing on relatives' risks of future disease

tion has elected not to perform the review, although it has the legal authority to do so.[6] The Task Force on Genetic Testing indicated it was "concerned about the quality of information made available to providers and consumers" and emphasised the role of the provider in ensuring that potential test users receive accurate information.[6]

In the United Kingdom, the terms of reference of the Advisory Committee on Genetic Testing include: "to establish requirements, especially in respect of efficacy and product information to be met by manufacturers and suppliers of genetic tests."[12] This could lead the committee to examine the need for review of genetic testing protocols by research ethics committees. It has published a policy for genetic testing without the involvement of a doctor; this was prompted by a company that offers cystic fibrosis carrier screening directly to the public for a fee of £95 per couple. The policy states that carrier testing for inherited recessive disorders with childhood onset, like cystic fibrosis, can be obtained directly by individuals without the intervention of a healthcare provider unless there is a family history of the disorder.[12] (On the matter of direct testing, the United States's Task Force on Genetic Testing proceeds more cautiously: "The Task Force discourages advertising or marketing of predictive tests to the public."[6])

Improving laboratory quality

In both the United States and the United Kingdom it is generally agreed that laboratories performing clinical tests should be subject to external quality control. In the United States, the Clinical Laboratory Improvement Amendments passed by Congress in 1988 provide some control but none specifically for genetic tests. Laboratories can voluntarily participate in proficiency testing and inspection programmes for genetic tests offered by professional associations. A few laboratories do not participate in any proficiency testing programmes.[23] The Task Force on Genetic Testing recommends the creation of a genetics specialty under the amendments. Once it is established, every laboratory performing genetic tests will have to comply with the specialty requirements.

In the United States, most clinical laboratories are private and many are run for profit, but most of those in the United Kingdom are associated with health authorities and are subject to Department of Health rules. The Clinical Molecular Genetics Society established a quality assurance scheme, now operated by an independent body. By 1995 it was assessing the quality of testing for eight specific genetic disorders.[24] Assessment has now been considerably extended to more diseases. A proposed European Union directive on in vitro diagnostic medical devices provides greater assurance of the quality of tests marketed as kits and reagents.[25] As is the case in the United States, this Directive does not extend to tests provided as services.

The therapeutic gap

It has proved far easier for scientists to develop tests for genetic diseases than to devise effective interventions to prevent manifestations in people who are born affected. This therapeutic gap has already lasted over 10 years for Huntington's disease, Duchenne muscular dystrophy, and cystic fibrosis. For all three of these disorders, prenatal diagnosis and termination of pregnancy can be used to avoid the birth of an affected child. This option is not acceptable to people who oppose abortion on religious or moral grounds. Among those who do not oppose abortion entirely, questions still arise about pregnancy termination for adult onset disorders, like Huntingdon's disease, or for disorders whose prognosis is improving, like cystic fibrosis, and for which gene therapy is already being

Definition of genetic tests

"The analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect inherited disease-related genotypes, mutations, phenotypes, or karyotypes, for clinical purposes. Such purposes include predicting risk of disease, identifying carriers, establishing prenatal and clinical diagnosis or prognosis. Prenatal, newborn, and carrier screening, as well as testing in high risk families, are included. Tests for metabolites are covered only when they are undertaken with high probability that an excess or deficiency of the metabolite indicates the presence of inherited mutations in single genes" (Task Force on Genetic Testing[6]).

This definition excludes tests conducted purely for research, tests for somatic (as opposed to inherited) mutations, and testing for forensic purposes; it also excludes eliciting genetic information from a family history.

Government responses to the implications of genetic testing

In the United States, a joint working group of the National Institutes of Health and the Department of Energy on ethical, legal, and social implications of human genome research was created in 1990.[10] It has now been disbanded. This group created two task forces to make policy recommendations on the implications of genetic testing.[6, 11] In the United Kingdom, a non-statutory Advisory Committee on Genetic Testing was created in 1996. It has issued a report on offering genetic tests direct to the public.[12] The government established the Human Genetics Advisory Commission in 1996 to review scientific progress, report on issues that have "social, ethical, and/or economic consequences, for example in relation to public health, insurance, patents and employment" and to "advise on ways to build public confidence in, and understanding of, the new genetics."[13] It has recently published a report on the implications of genetic testing for insurance.[14]

Genetic limitations of genetic testing

For single gene (mendelian) diseases, the finding that a healthy person possesses a disease causing genotype will be highly predictive that future disease will occur, but:

- Expression cannot be forecast with great accuracy (variable expressivity). For instance, the severity of the lung disease in cystic fibrosis cannot be predicted very well by the genotype[15]
- Not all disease causing genotypes will be detected because many mendelian diseases can each result from several different inherited mutations at one gene locus (allelic diversity) or several loci (genetic or locus heterogeneity). Often, current technology cannot detect all of them. Over 600 mutations cause cystic fibrosis,[15] but the best technology available for clinical testing can detect no more than 90% of white carriers; the percentage is smaller in other racial groups

In contrast with the mendelian diseases, in common disorders, usually of adult onset, in which a genetic role has been identified:

- Inheritance of a relatively rare mutation may increase risk but does not always result in the disease (incomplete penetrance). For instance, the lifetime risk of breast cancer among a relatively unselected group of Ashkenazi Jewish women with the susceptibility conferring BRCA1 or BRCA2 alleles is less than 60%.[16] The risk is higher when multiple cases occur in families, suggesting that other gene loci as well as environmental factors influence the appearance of disease
- Genetic polymorphisms, which occur in 1% or more of the population, may contribute to the appearance of disease, but most people with the risk-increasing form of the polymorphism will never develop the diseases. For instance, fewer than 30% of people with the apolipoprotein E4 polymorphism develop Alzheimer's disease[17]
- Alleles of single genes play a significant role in only a small proportion (usually less than 5%) of all people with common diseases. This is the case for breast[18] and colon cancer[19] and Alzheimer's disease[20]

attempted. Marteau and Croyle have discussed issues related to the therapeutic gap.[5]

Although treatments are available for some of the common, complex disorders, such as breast and colon cancer, their safety and effectiveness in asymptomatic people found to have genetic susceptibilities to these disorders have not been established.[26, 27] In families in which disease is known to be associated with a specific inherited susceptibility mutation, a negative test result greatly lowers the chance of future disease and could help dispel concerns about the need for special surveillance or prophylactic surgery.[28] In the absence of a known inherited susceptibility mutation in the family, a negative test result for genetic susceptibility to a common disorder affects risk estimates negligibly.

Interest in some predictive genetic tests wanes as people are told of their limitations,[29, 30] but people are not always fully informed. The American task force emphasises that information on the risks and benefits of tests must be presented "fully and objectively" and that informed consent should be obtained.[6] Genetic testing could be inflicted on ethnic minorities when they are not informed of the implications of testing.[31] In the United Kingdom, there is evidence that patients with haemoglobinopathies, many of whom come from minority groups, are not always looked after in the best possible way.[32]

Discrimination and breaches of confidentiality

In the United States, some people cannot afford health insurance and others are denied coverage (or covered only if they can pay very high premiums) because of past illness. Asymptomatic people have been denied insurance (or charged higher premiums) because they were at risk of genetic conditions,[33-35] although it is difficult to gauge the extent of the problem. The ability of genetic tests to predict future risks could also be used to deny insurance. The solution to this problem has taken two forms, both involving legislation. The first is to deny health insurers the opportunity to use genetic test results, or knowledge that a person has had a genetic test, to deny insurance to healthy people. In some cases, the denial extends to genetic information as embodied in a family history. The second is to deny health insurers access to genetic test results or information without the explicit consent of the person being tested even though insurers will often pay for these tests. Both approaches would help reduce people's apprehension that having genetic tests would cause them to lose their insurance.[36] Over the opposition of the insurance industry, 26 states in the United States have passed laws barring health insurance discrimination on the basis of genetic testing or information.[37, 38] At the federal level, the Health Insurance Portability Act and Accountability of 1996 specifically prohibits the use of genetic information to deny group health insurance coverage when workers switch from one job to another.[37] The second approach, which is part of the bigger picture of assuring the privacy of medical records in general, is currently being explored at the federal level.

With the NHS assuring everyone some care in the United Kingdom, more attention has been focused on discrimination in life insurance. The recently published Association of British Insurers Code of Practice addresses these issues for all types of insurance (box).[39] Refusal to hire workers because testing shows they are at increased risk of disease is also a concern. American employers can no longer decline to hire someone on the basis of genetic information as long as the person can perform the essential functions of the job without threat to himself or herself or to others. After workers are employed, employers can exclude from their health insurance disorders whose future occurrences are predicted by genetic testing, as long as there is an actuarial basis for doing so.[41] Thus far in the United Kingdom terms of employment seem not to have been a constraint on health care, nor has health care constrained people to refrain from moving jobs. Only one employer's genetic screening programme could be identified in 1993 and it seemed to meet the very stringent conditions that had been suggested by the Nuffield Council on Bioethics.[42]

A person's genetic test results may have a bearing on relatives' risks of future disease. Until recently, there seemed to be a strong consensus in both the United States and Britain that health providers had a duty to protect the confidentiality of genetic information obtained from patients and not to convey it to relatives except when, in the most dire circumstances, the tested relative refused to do so.[42 43] In a recent case in New Jersey, an appeals court seemed to take a more permissive view: when a woman with familial adenomatous polyposis brought suit against the estate of her deceased father's deceased doctor for not warning relatives of their risk 20 years earlier, the court remanded the case for trial to determine whether the duty to warn relatives was breached.[44] Meanwhile, the House of Commons Select Committee veered in the other direction, maintaining that if counselling cannot persuade someone to share genetic risk information with his or her relatives, then the individual's decision to withhold information should be respected.[7] The law on this matter in the United States is far from settled. The Task Force on Genetic Testing emphasised that in offering genetic tests "providers must make clear that they will not communicate results to relatives, except in extreme circumstances," which the provider should define.[6]

Conclusions

Both the British and American governments have been slow to respond to issues raised by the potential spread of genetic testing. Current policies do not assure that sufficient data on the predictability of genetic tests will be collected before they enter clinical practice, that laboratory quality will be high once tests are used clinically, and that test results will be useful to those who are tested. Confidentiality of test results and specimens, psychological problems, and discrimination based on test results are likely to be problems. Once these problems are satisfactorily addressed, the public will be assured that the genetic tests available will truly be to their benefit.

In both countries, the efforts to address the problems of genetic testing have started with non-statutory advisory committees. The United Kingdom is now further advanced than the United States in establishing a governmental framework; two 1997 reports[12 14] marked the first use of that framework. The United States has considered many of the substantive issues in greater depth, as evidenced by the report of the Task Force on Genetic Testing,[6] recent analyses and policy statements regarding genetic discrimination in health insurance[45] and employment,[46] and the passage of laws at the state and federal level to reduce the danger of genetic discrimination. These issues cut across government agency and departmental lines, making action difficult. New legislation may be needed. Each country could benefit from examining the course taken by the other.

This series was edited by Theresa Marteau.

Genetic testing and life insurance

Early in 1997, the Association of British Insurers adopted a two year moratorium on asking people to take genetic tests when applying for life insurance. The association also said that genetic test results will not be used in providing life insurance of up to £100 000 that is directly linked to new applications for home mortgages; family history and other medical information will continue to be used. Decisions about use of genetic tests for other policies are up to individual companies. The association will continue to expect people to report the results of reliable and relevant genetic tests, and these results can affect the premium if the result indicates an increased risk.[39] Some major life insurance companies, however, have announced they will not require such reporting.[40]

The Human Genetics Advisory Commission has concluded that "it is unlikely that actuarially important genetic predictions of common causes of adult death will be available and validated for some time to come.... On balance ... the life insurance industry could currently stand limited adverse selection.... Concern about the perceived threat of discrimination by insurers ... remains an important issue and ... the Advisory Committee on Genetic Testing should keep the situation under review.... We recommend that for the time being the insurance industry should respect a moratorium on requiring disclosure of results of genetic tests."[14]

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Coping with loss

Bereavement in adult life

Colin Murray Parkes

This is the first in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

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BMJ 1998;316:856-9

Summary points

- Losses are a common cause of illness; they often go unrecognised
- Conflicting urges lead to a variety of expressions of grief; even so there is a pattern to the process of grieving
- A knowledge of the factors that predict problems in bereavement enables these to be anticipated and prevented
- Grief may be avoided or it may be exaggerated and prolonged
- Doctors can help to prepare people for the losses that are to come
- People may need permission and encouragement to grieve and to stop grieving

Doctors are well acquainted with loss and grief. Of 200 consultations with general practitioners, a third were thought to be psychological in origin; of these, 55—a quarter of consultations overall—were identified as resulting from types of loss.[1] In order of frequency the types of loss included separations from loved others, incapacitation, bereavement, migration, relocation, job losses, birth of a baby, retirement, and professional loss. After a major loss, such as the death of a spouse or child, up to a third of the people most directly affected will suffer detrimental effects on their physical or mental health, or both.[2] Such bereavements increase the risk of death from heart disease and suicide as well as causing or contributing to a variety of psychosomatic and psychiatric disorders. About a quarter of widows and widowers will experience clinical depression and anxiety during the first year of bereavement; the risk drops to about 17% by the end of the first year and continues to decline thereafter.[2] Clegg found that 31% of 71 patients admitted to a psychiatric unit for the elderly had recently been bereaved.[3]

Despite this there is also evidence that losses can foster maturity and personal growth. Losses are not necessarily harmful.

Yet the consequences of loss are so far reaching that the topic should occupy a large place in the training of health care providers—but this is not the case. One explanation for this omission is the assumption that loss is irreversible and untreatable: there is nothing we can do about it, and the best way of dealing with it is to ignore it. This attitude may help us to live with the fact that, despite modern science, 100% of our patients still die and that before they die many will suffer lasting losses in their lives. Sadly, it means that, just when they need us most, our patients and their grieving relatives find that we back away.

Recent approaches to loss

A 1944 study of bereaved survivors of a night club fire focused attention on the psychology of bereavement, and led to the development of services for the bereaved and to other types of crisis intervention services.[4] It established grief as a distinct syndrome with recognisable symptoms and course, amenable to positive or negative influences. This, in turn, fuelled interest in the new fields of preventive psychiatry and community mental health. Elizabeth Kubler Ross's studies extended this understanding to dying people,[5] and helped to provide a conceptual framework for the humanitarian work of Dame Cicely Saunders and the other pioneers of the hospice movement.

More recently the improvements in palliative care have led to improvements in home care for the dying. Home care nurses have bridged the gap and general practitioners have had a central role, not only in caring for dying patients and their families but also in supporting people through many other losses. This is