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Genetic testing and health insurance: Can they coexist?

MANY PEOPLE are ambivalent about genetic testing. On one hand, it can be of tremendous value in identifying people most at risk for a disease, allowing them to take early preventive and diagnostic measures.

On the other hand, many fear genetic testing will lead to discrimination in health insurance and employment. The history of eugenics is an example of applied genetics gone awry.

However, the issues surrounding genetic testing are fundamentally the same whether we are talking about a low-tech history and physical examination or testing for “disease genes” with DNA chips.

Thus, while we objectively examine the questions raised by recent advances in genomics and how they affect health insurance, we also must think about what we as a society can reasonably expect from health insurance companies.

See related article, page 12

■ BILL UNDER CONSIDERATION

In this issue of the *Journal* (page 12), Dr. Maurie Markman discusses the issues surrounding genetic data and genetic discrimination. Citing the dangers, he calls for restricting the use of genetic information by insurance companies and employers.

And in fact, in mid-October of 2003, the US Senate unanimously passed S. 1053, the Genetic Nondiscrimination Act of 2003, to protect the privacy of genetic information and prevent health plans, insurance carriers, and employers from discriminating on the basis of genetic information. This bill is now awaiting action by the US House of Representatives,

which is not expected until next year.

But this bill, like Dr. Markman’s article, raises some difficult questions. Precisely what genetic information should health plans and insurance companies be barred from using? And how real is the risk that people truly will be denied health insurance solely on the basis of a genetic test?

■ INSURANCE IS ABOUT DISTRIBUTING RISK

Insurance is about distributing risk—and about discriminating between people at high risk and low risk. Insurance companies are businesses, and to survive, they have to function like businesses. The question is how much discrimination is appropriate in the insurance arena.

Actuaries for health plans, auto insurance, and life and disability insurance use data on individuals in very different ways. Your insurance premiums may be calculated on the basis of your geographic location (homes in hurricane-prone areas might require higher hazard insurance premiums), age (teenagers pay higher auto insurance rates), sex (men die younger than women, raising their life insurance rates), and trends in medical care. Ratings may be based on the experience of the group to be insured (higher rates for physician pilots), the insurance company’s tables (based on its own experience), or a blending of those factors.

■ WHAT IS GENETIC INFORMATION?

The concept of genetic information is more complex than it seems. We all agree that a DNA test produces genetic information. But

What does society want? And how will we pay for it?



what about a complete blood count? Is it not a genetic test if it is used to diagnose a hemoglobinopathy? Height, blood type, sex, and even weight all reflect genetic information. For example, one of the key markers of Marfan syndrome, a genetic disorder that predisposes to aortic dissection, is a long, thin habitus. However, many people with this appearance do not have a genetic disorder.

How genetic information is defined may affect people's access to health care. For, given the current genetic discoveries, is not almost all disease ultimately genetic? Will insurance costs escalate as more diseases are found to be genetic and are eliminated from the assessment of risk? As access to more of this growing body of information is barred to insurers, then health insurance may cease to exist.

■ A PROPOSAL TO REDEFINE 'PREEXISTING CONDITION'

Time, implementation, and court decisions will reveal whether the recent legislation will prevent inappropriate discrimination. It may not be possible to solve the enormous problems of the health care system with one law, but it is possible to begin to explore new avenues of solutions.

Genetic disease is, in fact, medical disease. Rather than try to discuss which diseases should be included or excluded under this law, it may be better to look for alternative solutions.

Define preexisting conditions by signs and symptoms, not DNA tests

Various states have different waiting periods for preexisting conditions. While uniformity may not be attainable for the waiting period, perhaps the definition of a preexisting condition could be uniform nationally.


If we characterize a "preexisting condition" by the symptoms and signs of the disease, this definition would retain the appropriate discrimination or distribution of risk. A person with a positive DNA test (indicating a likelihood of future development of a disease) but no symptoms would not be said to have a preexisting condition. He or she would not have the disease until the symptoms allow the diagnosis to be confirmed.

This definition would allow people to seek early testing so that they can take steps to decrease their risk and plan for the future. If a health plan needs to examine a patient's pedigree to establish that a request for testing meets its criteria depending on the inheritance pattern, the physician can send this information without identifying name, sex, or age.

■ WHAT DOES SOCIETY WANT FROM INSURERS?

If insurers are forbidden under any circumstances from using genetic information to adjust premiums, then we are on the highway to eliminating insurance. If this is the expectation or becomes the outcome of this and future legislation, then it is time to start diligently working on a plan to cover health care costs.

If society decides that everyone is entitled to comprehensive health care, then all members of society must be prepared to bear the financial burden. If we expect the government to pay, then we must remember that we, the taxpayers, are the ones who ultimately pay.

Health care may be a right, but rights come with responsibilities. Are we, as a society, ready to be responsible for developing an infrastructure to deal with all the issues? 

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