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Discrimination Is Good

By Douglas I. Kalish   08/06/2002

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Modern-day anesthetics are a miracle for most of us. But for about 1 in every 20,000 patients given routine gas anesthetics, their muscles quickly become rigid, they develop a high fever, hyperventilation and an irregular heartbeat. Unless the anesthesia is immediately stopped and corrective drugs are administered, death is inevitable. These patients are normal in every respect except one: they have a defective gene that codes for the gate that lets calcium into muscle cells.
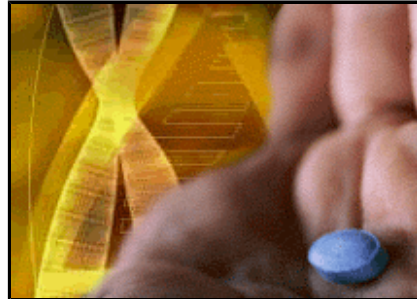
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Would you like your anesthesiologist to know whether you carry the defective gene before you get to the operating table? Then you'll have to share your genetic information with her.

Many drug therapies today are effective for only a subset of the population. Genentech has developed a therapy (Herceptin) specifically for women with breast cancer who over-produce a gene product called HER-2. Treatment with Herceptin will have no effect on women whose breast cancer is due to other causes and in fact could have dangerous side effects. A diagnostic test is available that identifies women with the HER-2 gene who could benefit from Herceptin therapy, thus targeting a therapy to a specific genetic profile.

Would you like to make sure that your Herceptin therapy is actually appropriate for your type of cancer? Is it reasonable for your insurance company to want to know whether the drug it is paying for will actually work for you? If you think so, you'll have to share your genetic information with them.

The revolution in biotechnology is not just creating new drugs to cure our diseases, it is giving us the tools to identify the propensity for disease at the individual level. While the development of gene-based drug therapies tends to grab the headlines, it goes hand-in-hand with the creation of diagnostics from genetic information to identify disease.

The benefits of gene-based testing to patients will be unambiguous. Your doctor can treat you as the individual that you are, recognizing the idiosyncrasies of your genetic profile, your body and your metabolism. This is a good form of discrimination - treating you differently from other patients based on the facts of your genetic makeup.

It's not a secret that many well-known allergy drugs work for only half the population. The reason? Genes, again - the ones that code for the chemicals that turn the drugs into active ingredients in your body. Before you shell out your money on an expensive prescription, wouldn't you like to know whether it works for you? The promise of gene-based testing means getting the drug that is right for you.

But there is a difference between discrimination in healthcare and

discrimination in health coverage. Of course you want your doctor to know whether a drug or therapy is right for you, but do you want to be denied insurance because of a predisposition to a genetically-related disease?

The insurance paradigm is turned on its head by biotechnology. Traditionally, insurers use statistics and actuarial tables to determine the likelihood of illness in a population and pool the premiums and benefits of healthcare and life insurance over a large group. Biotechnology, and specifically genetic testing and tailored therapies, disrupts the insurance paradigm because it injects much more reliable information on the propensity of disease and cure at the individual level.

On the positive side, knowing the genetic profile of a patient should allow doctors to select the most clinically effective and the most cost effective course of treatment. When these therapies reduce the costs to the insurers, they will include these therapies as part of the health benefit package. However, therapies and treatments where the cost savings are uncertain, have many years to materialize, or are preventative are less likely to be included even if there is a clear clinical benefit, because the cost reduction won't flow to the insurer. Insurers are developing sophisticated cost-based analyses, known as pharmacoeconomics, to justify payment for specific therapies.

On the negative side, genetic information about an individual will enable insurers to identify those who are likely to develop a disease. In theory, insurers could more closely determine profitability on a per-patient basis, because they can more accurately predict who is a "bad" risk versus a "good" risk and can establish premiums that reflect an individual patient's risk level. In the absence of legislation or social pressure to solidify community and average premium rating, the availability of personal genetic information will increase the spread of health insurance premiums that are much closer to an individual's real cost.

Genetic testing offers the ultimate in healthcare discrimination. We'll know our individual susceptibility to disease and be able to select the therapies that we'll know are right for us. With these advantages, we will be highly motivated to agree to genetic testing when asked. However, we will have to weigh the potential that the same genetic information might be used to restrict or deny us insurance coverage. This conflict will dissuade many people from pursuing gene testing and therapy until the stipulation of personal information produces clear personal and tangible benefits.

The author is a professor at the Haas School of Business, University of California at Berkeley.

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