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Should Genetic Information Be Treated Separately?

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Incomplete patient charts? "Shadow" files? Though such practices sound as fishy as 2 sets of account books, federal and state legislative initiatives regarding genetic information could lead physicians to start keeping these sorts of double or shadow files. The belief that genetic information should be filed separately from other medical information and handled with special attention to confidentiality was termed "genetic exceptionalism" by the Task Force on Genetic Information and Insurance, an NIH-DOE joint working group of the Human Genome Project [1].

Ethicist Thomas Murray explains the main arguments in support of genetic exceptionalism [2]. The first points to the prophetic nature of genetic information. Whereas medical records detail the illnesses we have had and chronic conditions we now have, genetic testing can predict what we are likely to get in the future. Someone who is perfectly healthy and passes a pre-employment or health insurance physical with flying colors may be discovered, after genetic testing, to be predisposed to develop high cholesterol, breast or colon cancer, Huntington's or Alzheimer's disease. On this view, our genomes are, in the words of Murray's title, "future diaries." Genetic exceptionalism proponents claim that this prophecy should not be part of an individual's medical records. Insurance companies, on the other hand, argue that it's not fair for prospective policyholders to have information about their health that the prospective insurer doesn't have. That, they say, is like cheating at cards or signing up for home-owner's insurance when the fire truck's on the way to your house.

Our Genes "Inform On" Others

A second aspect of genetic test results that sets them apart from a simple history of our illnesses, past and present, is that such results can reveal information about family members' information that they themselves may not have, may not want to have, or may not want others to have. In the case of an autosomal dominant mutation, such as that associated with Huntington's disease, presence of the mutant allele in a young adult, call him Alex, means that one of his parents likewise has the dominant allele. If one of Alex's maternal grandparents had Huntington's, then his mother has the allele and transmitted it to Alex. (If a paternal grandparent had the disease, then Alex's father transmitted the allele.) Alex's mother may have avoided testing and wishes not to know whether or not she has the mutation. Alex's positive test result, however, will confirm that she does. Not all implications for kin are this dramatic; test results can designate others as carriers, for example. Test results can

also uncover an adoption or "false paternity," a misleading term that really means "false paternity claim"--the person calling himself the father is not the biological father.

Genetic Information Has Been Abused

Finally, genetic exceptionalists argue that past abuses of genetic information warrant special vigilance and preventive action. They refer not only to the infamous and heinous abuses of Nazi Germany, but to marriage restriction, sterilization, and even immigration policies in the US from the second decade of this century well past mid-century. Results of genetic information might now be used, some fear, to discriminate not only against those who exhibit symptoms of physical and mental conditions such as Huntington's or Alzheimer's disease, alcohol dependency, and psychosis but also against those with a genetic predisposition or "gene for" such conditions.

Genes Are Not the Sole Predictors

Murray disagrees with the genetic exceptionalism position, reasoning that, for one thing, it relies on what he calls the "2-bucket theory of disease" [3]. This theory would divide all diseases and disorders into 2 categories: genetically transmitted illness and non-genetic illness. Such is not the case, Murray asserts. Genetic influences on, to take one example, the fortitude of one's immune system, affect how frequently one contracts common colds and the severity of those colds. Yet, no one would refer to the cold or to flu as a genetic disease. Very little about our health has no genetic component, and, at the same time, very little about our health is determined only by our genome, much less by one gene.

The attempt to separate genetic information from non-genetic information is doomed, Murray thinks. Much of a patient's family history and personal health history is genetic information, but is not labeled as such because it is not the result of genetic testing. Must physicians stop a patient in the middle of a history and switch to a different, more secure set of records when the patient begins to list the illnesses and causes of death of his parents, grandparents, and other family members?

The impossibility of disentangling genetic from non-genetic information renders most state regulations on the privacy of genetic information ineffectual because most state regulations to date require special protections for results of genetic testing only. An employer or insurance company can reject a prospect or classify him as high risk for future heart disease, cancer, diabetes, Alzheimer's or Huntington disease on the basis of family and health history that would be released to them under most current legislation. For this reason, legislation and regulations that cover all patient records (such as President Clinton's executive medical records privacy order in late December 2000) will offer a more effective approach to protection against genetic discrimination.

"Genetic Exceptionalism" is Ethically Unjust

There is also a compelling ethical reason for not acceding to the plea for genetic exceptionalism: to do so would give preferential protection to someone who contracts a disease from so-called genetic causes. There is "no good moral justification for treating genetic information, genetic disease, or genetic risk factors as categorically different from other medical information, diseases, or risk factors" [4]. If genetic exceptionalism safeguards were in place, an insurance company could not deny coverage to a woman who has a BRCA gene on the basis of that test result. Yet a woman who had not been tested or who had tested negatively could be denied coverage on the basis of family history. When someone needs medical care, Murray argues, he or she needs medical care. To say that the care will be reimbursed only if the cause is genetic, in the most simplistic definition of that term, is unjust.

For these reasons, Murray and the Task Force on Genetic Information and Insurance ultimately concluded that genetic information should not be given special protection. Rather, society must decide which third parties--employers, insurers, schools, and so on--have the right to our medical records, including family histories, and under what circumstances they may have them. Then we must enact the proper rules and regulations to see that those conditions are met and penalize violators.

References

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3. Murray, Genetic exceptionalism, 67
4. Murray TH. Genetics and the moral mission of health insurance. *Hastings Cent Rep*. 1992;22(6):12-17.

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