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# Pride and Prejudice: Avoiding Genetic Gossip in the Age of Genetic Testing

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## INTRODUCTION: THE PROMISE OF GENETIC INFORMATION

Genetic testing holds increasing promise. As accurate, comprehensive, and inexpensive genetic testing becomes increasingly available, it becomes possible to measure the probability and magnitude of various maladies, making detection, treatment, and prevention all the more effective. So great is the promise that recently there have been increasing calls for including genetic information as a dimension even in revisions of the standard diagnostic nomenclature of such a far-afield specialty as psychiatry, as it proceeds with its fifth edition of the *Diagnostic and Statistical Manual (DSM V)*.<sup>1</sup>

## MEDICAL INFORMATION GOES CYBERSPACE

However, the advent of the age of routine genetic testing for medical and behavioral conditions, together with the increasing computerization of information and its transmission in cyberspace, raises security concerns that sensitive information not be used in ways that could be harmful; should security fail, it is important that methods of collecting information not compound the loss of privacy with helplessness and distrust, which are the special handmaidens of loss in the context of unconsented-to risk.<sup>2</sup>

Genetic information has often been seen as immutable character — with character’s aura of destiny around it. Long before there was the concept of genes, Cassius comments on character to Brutus in Shakespeare’s *Julius Caesar*, “The fault, dear Brutus, is not in our stars, But in ourselves.”<sup>3</sup> All too often we now misunderstand genes as having the character of stars within us that determine our destiny. Even as genetic advances bring a deeper scientific and clinical understanding of the complexity of genetic influences on behavior, such reductionist fatalism regarding the role of heredity in character and choice is likely to persist and grow. Thus, safeguards need to be put in place to make certain that a patient’s personal genetic information will not be disclosed to others without the patient’s informed consent. Further, although genetic information is often subject to distortion and stigmatization due to its aura of destiny and inevitability, in and of itself it is ambiguous,<sup>4</sup> and as genetic information grows, it will be impossible to segregate it neatly from

other medical information, and there will be a great deal of room for distortion and mischief to make their presence felt.

Information that is the result of genetic testing needs to be handled with caution, as careless dissemination of personal information can create an environment in which nothing is sacred, which can cause patients to feel helpless and that they have lost their identity. Currently, under the Health Insurance Portability and Accountability Act (HIPAA), patients' confidential health information may be disclosed for medical operations without their informed consent. It appears that these informed consent provisions have been dropped as a kind of social policy experiment, which should, itself, have required informed consent.<sup>5</sup>

While the notion of "genetic discrimination" is relatively new, there are hundreds of instances in which individuals were denied employment or lost their health and life insurance based on perceived genetic abnormality.<sup>6</sup> "Genetic gossip" created by widespread circulation of individual genetic information can result in "genetic reductionism," which neglects the important role that the environment plays in the expression (or repression) of genetic potential. Genes are but one determinant of behavior — and genes alone cannot determine how individuals will grow and develop.

Nonetheless, all too often, sound bites trump complexity. Thus, when genetic information circulates as genetic gossip, it is not likely that its subtlety and complexity will be expressed as clearly as in a recent study by researchers at the University of California Los Angeles — who report that an individual's early or current environment can reverse the effect of a genetic variant linked to depression.<sup>7</sup> While individuals who are homozygous carriers of the short allele (s/s) of the serotonin transporter gene-linked polymorphic region (5-HTTLPR) may be at increased risk for depression, they were found to exhibit significantly less depressive symptomatology if they reported a supportive early environment or recent positive experiences.

## **GENETIC INFORMATION MEETS GENETIC REDUCTIONISM**

Genetic discrimination touches on many issues, including individuals' right to privacy and what this right includes, the possible consequences of the sharing of genetic information, and the current protections that the law provides — or fails to provide — to protect individuals' genetic information. Moreover, when an individual's genetic information is disclosed, the information may stigmatize not only the affected individual but his or her family members.

An individual's right to privacy is protected under common law, and arguably under the first five amendments to the Constitution of the United States. However, with the advent of technology that is capable of determining an individual's genetic makeup, it becomes necessary to determine whether this right to privacy includes the right to genetic privacy. For example, in 1995, employees of the Lawrence Berkeley Laboratory filed a class action lawsuit alleging that the laboratory had tested them for various medical conditions without their knowledge or consent. Specifically, the employees accused the laboratory of performing genetic testing for sickle cell trait, in addition to testing for venereal disease and pregnancy.

This case was heard on appeal by the United States Court of Appeals for the Ninth Circuit,<sup>8</sup> which ruled that the laboratory may have violated the employees' constitutional right to privacy by performing genetic testing without their prior consent. The case was sent back to the district court level for retrial. Subsequently, in August 2000, Lawrence Berkeley Laboratory agreed to settle the lawsuit for \$2.2 million and agreed not to test employees for pregnancy, syphilis, or sickle cell trait.

As technology improves and genetic tests become less expensive, individuals are increasingly at risk of having their genetic information exposed. This genetic information in turn can be used to discriminate against people who carry a gene that is tied to a specific disease. This can be particularly problematic because it may severely decrease an individual's prospects for employment, ability to secure insurance, or limit other opportunities in life, even when the person is clinically healthy and displays none of the symptoms of genetic disorder. As Sheri A. Alpert notes, "At its best, genetic information is highly probabilistic in nature. . . . The main difficulty with the nature of genetic information is that few lay people actually understand that probabilistic aspect, often believing instead that the presence of a mutation equates to the presence of a malady."<sup>9</sup>

In effect, the individual can become a victim of the folk beliefs and stereotypes that surround genetics and mental illness.<sup>10</sup>

Given the fact that human beings use heuristics — fast and frugal simplifying strategies for survival — we avoid information overload in the midst of ambiguity and uncertainty when speed is of the essence. Yet, given the structure of memory, such heuristically governed first impressions may often be our last impressions.<sup>11</sup> Thus, for uninformed third parties, a “genetic predisposition” may translate to inevitable impairment, regardless of the individual’s environment and choices. Such fatalism can easily feed prejudice that is founded on distortion of the meaning of heredity; such prejudice is invariably easier to maintain regarding others than it is regarding oneself. Allowing uninformed third parties to have unwarranted access to genetic information may not only undermine the goal of a just and fair society, but also create a self-fulfilling cycle of deepening and increasingly anachronistic genetic fatalism.

### **THE PROBLEM WITH HIPAA**

As the breadth of genetic knowledge continues to grow, it is not surprising that there are new complaints regarding genetic discrimination. Without adequate safeguards in HIPAA that require informed consent for the release of medical information, we can expect more cases similar to that of the Burlington Northern Santa Fe Railway (BNSF), in which the U.S. Equal Employment Opportunity Commission (EEOC) filed a suit against the BNSF for secretly testing its employees for hereditary neuropathy with liability to pressure palsies (HNPP), a rare genetic condition that causes carpal tunnel syndrome as one of its many symptoms.<sup>12</sup> The BNSF claimed that the testing was a way of determining whether the high incidence of repetitive-stress injuries among its employees was work-related or not. However, beyond simply testing for HNPP, company-paid doctors also were instructed to screen for several other medical conditions such as diabetes and alcoholism. BNSF employees were not told that they were being genetically tested, and an employee who refused testing was threatened with possible termination.

While in this instance the lawsuit was settled, without adequate privacy protections employees are likely to eventually find themselves in job environments in which they are not aware that their genetic information is being secretly accessed, and decisions such as promotion or retention may be made on covertly or subtly discriminatory grounds.

Current privacy protections are inadequate. While HIPAA provides some protection from discrimination, the protections it offers are incomplete. Much more is needed to ensure that genetic information is securely safeguarded. HIPAA does not prohibit the use of genetic information as a basis for charging a group more for health insurance. As a result, individuals who are genetically predisposed to certain conditions may be charged premiums that are so expensive that they are, in effect, uninsurable. HIPAA does not limit the collection of genetic information by insurers, nor does it prohibit insurers from requiring individuals to take a genetic test. Because of this, an insurer can demand a genetic sample from an individual as a prerequisite to becoming insured. Further, HIPAA does not limit the disclosure of genetic information by insurers: once an insurer acquires an individual’s genetic information, there is the risk that it may disseminate the information to other parties. Finally, HIPAA does not apply to individual health insurers unless they are covered by its portability provision. The public’s fears of irrational and rational discrimination by insurers are not unjustified, and should be addressed.<sup>13</sup>

### **CONCLUSION: THE LESSONS OF HISTORY AND PSYCHOLOGY**

Historically, genetic stereotypes have been used to reinforce prejudice.<sup>14</sup> This abuse has been exacerbated by a psychological tendency to continue in patterns of behavior.<sup>15</sup> If genetic information is not protected, the problem will worsen. It is of paramount importance that patients who are at risk of this abuse retain control of medical information that can be easily distorted and used for prejudicial purposes.<sup>16</sup>

The current system burdens patients with “opting out” of the system of shared medical information. There is a difference between opting out of having personal information shared and being asked to give

informed consent.<sup>17</sup> Patients who are frightened and demoralized may find it easier to "go with the flow." Patients who depend on their doctors for treatment may find a request for permission to release genetic information that has not yet been collected too abstract to be meaningful.<sup>18</sup> Thus, only a meaningful informed consent process for release of medical — and especially genetic — information, after the information has been obtained, can safeguard a vulnerable patient's autonomy<sup>19</sup> and only with such a process can the consent that is given be considered authentic.

As technology becomes more advanced and genetic information becomes more readily available, it becomes increasingly important to address the shortcomings of HIPAA. Without adequate privacy protection, the individuals who are most vulnerable to genetic discrimination are those most likely to be the victims of discrimination by employers who gain covert access to medical records — and these individuals lack appropriate legal recourse to timely and effective relief and remedy. As time goes on, an increasing amount of sensitive mental health treatment is being provided in general medical settings; in the same way, it is likely that an increasing amount of genetic information will be exchanged in these same settings.

In practice it is unlikely that general medical records can be purged of either sensitive mental health or genetic information, or that a Chinese wall, or information barrier, can be built between sensitive and non-sensitive medical information. Thus, there is a strong need to avoid genetic gossip, given the increasing presence of genetic information in routine medical charts, and the tendency for such information, when packaged categorically as encoded in electronic medical records, to be easily distorted by third parties and easily disseminated more widely than ordinary narrative medical information that is found in paper charts.

This is not to say that the privacy of genetic information should always be paramount, at all costs. As Stephen G. Pauker and Susan P. Pauker note, "When considering restrictions on information transfer, based either on HIPAA or on the precepts of medical ethics, one basic rule should be remembered: *Patient care and safety come first*. HIPAA contains explicit exclusions for treatment, payment, and health care operations: PHI [personal health information] that is required for these three purposes is exempt from HIPAA's restrictions."<sup>20</sup> Even from a cost/benefit perspective, however, we must re-examine the utility of the informed consent process in terms of promoting a more reliable patient history, empowering vulnerable patients, and promoting an ongoing doctor-patient alliance.

Acting today to provide an ounce of genetic privacy by re-establishing general HIPAA informed consent provisions for the release of any patient's medical information is consistent with good clinical care and patient safety. There is no convincing evidence that reinstating informed consent provisions will make payment processes or healthcare operations unwieldy. Because covered entities need to ask patients to sign HIPAA notices, for the same amount of effort, they can also ask for patients' consent. Furthermore, failing to use an informed consent process for the release of medical records containing genetic information may lead to an increased tendency toward "group think," such as overconfidence in interpreting often-ambiguous genetic information.<sup>21</sup> In such a situation, clinically useful information regarding genetic potential can be reduced to the equivalent of sound bites. When such clinically useful information is diluted in this way, the seeds of stereotyping and discrimination are sown. An ounce of genetic privacy, achieved via informed consent, is worth more than any pound of genetic discrimination cure tomorrow by the U.S. Equal Employment Opportunity Commission or the judiciary.

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## NOTES

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