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Safeguarding Genetic Privacy

by Anna-Marie Struble, Emily Valji, and Jennifer Lilly

It is the year 2021, and Ginger has just walked out of a job interview with Mr. Abe Horrent, recruiter for the modest-sized firm Gross & Inequity, Inc. While Ginger hops into her car feeling great about her interview and confident that she will get this job, Abe runs a credit history check, criminal background check, and a genetic profile check. The Genetic Profile is a new innovation, available to the public thanks to the hard work of the Human Genome Project researchers who have been able, after many years, to identify the genes responsible for every genetically caused/influenced disease and disorder known to man. This database allows people to view their genetic profiles (if they had genetic testing done) by searching with their social security number. Of course, employers also have access to this database, but the law prohibits job discrimination on the basis of information gained from genetic profiles. Now, Abe Horrent discovers that Ginger is homozygous for the DQB1-0602 allele, the primary genetic risk factor for narcolepsy, a sleep disorder characterized by excessive day-time sleepiness, irresistible sleep attacks, and cataplexy (episodes of paralysis in skeletal muscles). She also possesses other genes known as links to narcolepsy. Abe searches for “narcolepsy” on Google, and discovers that narcoleptics often need long naps in the middle of the day to manage their symptoms. Because the position is a desk job, there would be no risk of physical harm to her or her co-workers as a result of the disorder. Yet the possibility of her need for daily naps would greatly decrease her productivity. Abe Horrent decides to hire someone else to fill the position, even though Ginger is the most qualified candidate.

Since the completion in 2003 of the Human Genome Project’s initial goal to map all the genes and discover the complete nucleotide sequence in the human genome, opportunities for many significant medical advances have opened up to us, including gene therapies for various

genetically-linked medical disorders, the ability to create “custom-made” drugs, and early, reliable diagnosis of genetic predispositions to disease. Genetic testing, the inspection of a person’s DNA to identify mutated sequences, is medically relevant for individuals. However, along with the undeniable benefits this knowledge brings, serious questions have arisen concerning how this knowledge should be handled to protect the rights of individuals. Two major areas of concern are the “privacy and confidentiality of genetic information, and fairness in the use of genetic information by insurers, employers, courts, schools, adoption agencies, and the military” as noted on the Human Genome Project website (www.ornl.gov/hgmis). Obviously, as we noted in the case study, information gained from genetic testing may be abused. This paper will examine the role of healthcare professionals to ensure that such information remains protected. We will then discuss the moral responsibility to handle genetic information in an ethical manner. We will reflect on the traditional principles of medical ethics derived from the Hippocratic Oath to inform our thinking. Finally, we will briefly examine the laws and legal protections for individuals and their genetic information that have already been established.

The Hippocratic Oath has been the basis of medical ethics for the last two thousand five hundred years. Found in the *Corpus Hippocraticum*, the Oath outlines the duties and relationship of the physician to the illness, the patient, and to other physicians. The Hippocratic relationship between patient and physician has been especially formative in the history of medicine. Physicians are to treat all persons with the same respect and care (distributive justice), act in the best interest of the patient (beneficence), and to not harm the patient (non-maleficence). Confidentiality flows out of these principles: “What I may see or hear ... in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things

shameful to be spoken about” (Antoniou, 2010, p. 3077). Confidentiality protects patients; as healers, physicians should be ashamed to divulge their secrets.

Breaches of confidentiality break the Oath's ethical standards. There are many examples of "social stigmatization, loss of employment, or compromise of legal status" that occur because of poor or inappropriate judgments in this area (Hill, 2003, p. 1140). The emotional distress caused by the physician's lack of confidentiality is not an act of beneficence, but an act of maleficence, even if it is unintentional. Furthermore, distributive justice is denied when a physician specifically discusses patients with particular afflictions, including genetic diseases, with a third party (Hill, 2003). The values of the Hippocratic Oath all rely on the maintenance of confidentiality.

Patients expect physicians to not break confidentiality, and if they do, to be punished, according to a 2003 study by Plantinga and colleagues. Her team interviewed six-hundred and two individuals afflicted with a genetic condition, a serious non-genetic medical condition, or at risk of developing a medical condition based upon strong family history. Nearly all those interviewed disapproved of the idea of physicians providing personal medical information to health insurance companies (82.4%) and employers (96.61%) without permission. In fact, a majority of subjects believed that doctors should be punished for providing such information to insurance companies (72.9, average) and employers (80.3%, average). Patients desire the autonomy to control the release of their medical information but "generally trust their providers to release their information to the proper people and for the right reasons." (Plantinga, *et al*, 2003, p. 58).

Physicians sharing medical information, including genetic information, with third parties without express permission ruins the fiduciary relationship described in the Oath. The trust patients have in their physician to responsibly manage their personal information is broken. Without trust, the relationship between physician and patient is unharmonious and patients can no longer entrust their wellbeing to the physician. Physicians are shackled by the autonomy of a distrustful patient and cannot act on their behalf. The Hippocratic principles are needed to guarantee patient welfare and the vocation of the physician (Antoniou, *et al*, 2010).

Today, there is significant pressure to disarm the Hippocratic Oath. Many medical schools have altered the Oath with the "goal of creating a socially benign oath" with "nonbinding guidelines" so that it "would not serve to restrain the conscience" (Smith, 2008, p. 3). Safeguards against patient harm have been replaced with a legal duty to warn third parties. In the case *Tarasoff v Regents of the University of California*, physicians were held responsible to protect not the patient but any third party who might be harmed by the patient (Regan, Alderson, & Regan, 2002). This harm is vague and could be used to defend not employing an individual who might cause economic harm to a company. A duty to warn third parties and a weak Oath undermines the physician's responsibility to demonstrate beneficence and threatens to ruin the practice of distributive justice. Other safeguards need to be present.

Recent laws have attempted to protect a person's right to privacy concerning genetic information. These laws are not water-tight, but they consider genetic discrimination to be wrong. The Genetic Information Nondiscrimination Act (GINA), probably the most important effort to protect genetic information, was signed by President Bush in 2008. GINA makes it illegal for an employer to make a decision on a potential employee — or for a health insurance agency to determine eligibility — based on genetic factors (Francis, 2010; Hudson, 2008).

While GINA protects genetic information to some degree, there are still ways to “get around” it. For example, The Family Medical Leave Act (FMLA) allows an employee to request leave to receive medical treatment (or to care for a family member who is receiving medical treatment), but GINA allows the employer to require confirmation of the necessity of the leave, such as the employee’s medical history (Francis, 2010). Also, GINA does nothing to prevent genetic information from being obtained indirectly; people can be genetically discriminated against even if they have never actually had genetic testing. According to one report, “A guy I knew had an identical twin brother who had liver disease and died. The guy I knew was asymptomatic, but couldn’t get life insurance at the normal rate. He didn’t have to be tested. If his identical twin had it, he had it” (Klitzman, 2010, p. 74). Additionally, discrimination does not always occur in an outright fashion. Klitzman also relates the example of an employer intentionally giving someone projects that are less desirable because of some genetic abnormality — this would be another, harder to prove, form of discrimination.

There are some things that GINA does not even attempt to address. GINA does not contain any prohibitions for genetic discrimination concerning life or long-term care insurance (Hudson, 2008). It also does not require employers to make accommodations for those who have a genetic predisposition to a problem that may be made worse by environmental factors. Because these individuals are currently asymptomatic, they would not be covered by the Americans with Disabilities Act. This could be considered a type of discrimination as well, because a person who knows that exposure to certain things will exacerbate his condition will naturally want to limit that exposure, and if his workplace will not accommodate him, he may have to quit (Klitzman, 2010).

Individual states have also enacted their own laws concerning genetic privacy and discrimination. GINA does not abolish state laws; it acts with them to provide more protection (Hudson, 2008). Executive Order 13,145 (which protects only federal employees) was issued in 2000. “The order bars federal employers from obtaining or disclosing ‘protected genetic information,’ which includes information about the genetic tests of an individual or her family members, or information about the occurrence of a disease, medical condition or disorder in the individual’s family members.” It also states that federal employers cannot discriminate in any way on the basis of genetic information. The order does, however, give permission for federal employers to request access to genetic information in certain circumstances (Eltis, 2007, p. 286).

Even though there are legal protections against genetic discrimination, people must be informed for these protections to be effective. If a person gives permission for his health information to be released, he needs to insist on protection for his genetic information. People also need to know they are not required to undergo genetic tests if asked to do so by an insurance company. At the very least, they should specifically ask how results from such tests will be stored (Francis, 2010; Hudson, 2008).

The ability to discover genetic information about ourselves through genetic testing is a wonderful thing and holds promise for future medical and scientific advances. However, this wealth of information is also subject to abuse, and that abuse could have a devastating impact on the lives of individuals. Physicians and other medical professionals, who have the most ready access to the genetic information of patients, have the moral responsibility to guard their patients’ well-being. They have a duty to preserve and encourage the patient flourishing by respecting patient autonomy, showing beneficence, refraining from maleficence, and treating all

patients in a just manner. They have a huge role to play in safe-guarding genetic information and ensuring that it is used in an ethical manner.

As we discussed, several laws already protect genetic information, but they fall short of completely eliminating the possibility for discrimination. A re-examination of current statutes is needed, and perhaps revisions are in order. There is much at stake: whether or not we take steps now to ensure the safety of genetic information will greatly influence what sort of ethical monsters we may deal with in the coming decades.

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