

ABSTRACT

ASUNTOS LEGALES Y ÉTICOS EN EL USO DE LA INFORMACIÓN GENÉTICA: UNA PERSPECTIVA ESTADOUNIDENSE

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Debido a que el tema de las implicaciones legales y éticas de la genética humana es muy amplio, se puede dividir en dos grandes ramas: las implicaciones relativas al diagnóstico y tratamiento clínicos y las relacionadas con asuntos no médicos. Precisamente este trabajo se refiere a las segundas.

Es en principio se citan dos casos en los cuales la información genética ha sido utilizada con fines no médicos.

Es el primero, publicado el 21 de junio de 1995 en el *New York Times*, relata como gracias a un examen de ADN se identificó a un niño que había sido raptado por el ejército salvadoreño trece años antes y fue devuelto a su madre.

ES el segundo, publicado el 23 de octubre de 1995 en el mismo periódico, se refiere a las investigaciones realizadas por un grupo de investigadores de la Universidad John Hopkins en Baltimore, en las cuales se ha encontrado, a través de estudios a ratones machos, que la ausencia de un gen esencial para la producción de óxido nítrico los hace más agresivos con su pareja, llegando incluso al punto de matarla. Por lo que dichos investigadores sugieren que este descubrimiento algunas formas de agresividad humana.

Estos dos artículos ilustran de manera clara el dilema de la información genética, tanto para lograr reunir a una familia, como para intentar, con base en un experimento a ratones de laboratorio, darle una explicación genética a la violencia.

III. Existen, según el autor, ocho áreas en las que la información genética puede ser utilizada con fines no médicos:

1) Identificación. La técnica del ADN puede utilizarse para identificar familiares, como pruebas en casos de violación y asesinato, o para identificar cadáveres en caso de accidentes aéreos.

2) Empleo. En este rubro existen dos formas en las que la utilización de información genética puede ser útil para los patrones: la primera consiste en que algunos rasgos genéticos hacen a las personas más susceptibles a tener ciertas enfermedades, y la otra, en que los patrones no contrataran gente que tenga posibilidad de desarrollar alguna enfermedad genética en el futuro.

3) Seguros. Es probable que las personas que saben que tienen la posibilidad de contraer alguna enfermedad, compren un seguro médico de cobertura más amplia, pero si adquiriesen estos seguros a precio normal, las compañías de seguros quebrarían. Por eso las compañías de seguros exigirán los cada vez más comunes exámenes genéticos. De hecho, en los Estados Unidos diez estados prohíben que dichas compañías soliciten estos exámenes.

4) Relaciones comerciales. Para ilustrar este punto, se cita el ejemplo de una hipoteca sobre una casa por treinta años. En este caso la compañía hipotecaria seguramente deseará saber si el individuo vivirá, por lo menos, durante los siguientes quince años, para poder cubrir su deuda. Por lo que no es difícil imaginar que dentro de algunos años se requerirá junto con el "reporte de crédito" un "reporte genético".

5) Derecho de familia. La Información genética puede ser utilizada en diversas situaciones en el derecho de familia. Por ejemplo, en relación con la custodia de un hijo, existió un caso en el que el padre argumentaba que la madre no podía tener la custodia del hijo porque, de acuerdo con exámenes genéticos, era propensa a contraer la enfermedad de Huntington. También, puede realizarse un examen genético a la pareja que desee adoptar un niño, o por el contrario, al niño que desee ser adoptado.

6) Educación. La información genética puede ser utilizada en todos los niveles, desde la educación básica hasta la universidad. Actualmente en los estados de Colorado y Georgia se realizan exámenes genéticos a los alumnos para diagnosticar una de las enfermedades hereditarias más comunes de retraso mental.

7) Criminología. Se mencionaron ya las investigaciones que se están realizando respecto a una posible relación entre la violencia y los genes. ¿Podrían utilizar los jueces la información genética al momento de dictar una sentencia? 8) Conflictos en caso de lesiones personales. Pueden surgir acciones legales en contra de los médicos, por negligencia al momento de aplicar los exámenes genéticos.

En conclusión, el reto será poder utilizar la información genética de la mejor manera posible, tratando de asegurar que los beneficios sean para la mayoría.

LEGAL AND ETHICAL ISSUES IN THE USE OF GENETIC INFORMATION: A UNITED STATES PERSPECTIVE

Mark A. ROTHSTEIN

Good afternoon. I want to thank the organizers of this conference for their kind invitation to speak here and for their hospitality. I also want to commend them for their choice of topic. The issues raised by the human genome project and new genetic discoveries are extremely important to all peoples. New genetic discoveries hold great promise in the prevention and treatment of some of the

most dreaded diseases. Yet, there is a great challenge to ensure that genetic information is used only for the benefit and not the detriment of the individual.

The topic I was asked to address, legal and ethical issues in genetics, is extremely broad. One way of dividing the issue is to separate issues related to diagnosis and treatment, clinical genetic issues, from issues related to the use of genetic information for nonmedical purposes. I would like to address this latter issue. With your indulgence, I would like to deliver the remainder of my speech in English.

Two news stories appearing in the last year provide examples of how genetic information may be used for nonmedical purposes both for good and for bad.

The first story appeared in the January 21, 1995 issue of the New York Times (Barbara Crossette, "DNA Test Reunites Salvadoran Mother and Child").

In the first case of its kind to arise from the civil war in El Salvador, a mother and her child were reunited yesterday after a DNA test identified the boy as the one taken away by the Salvadoran Army nearly 13 years ago, when he was a six-month-old baby.

Physicians for Human Rights, a Boston-based organization, announced the DNA match yesterday in the capital, San Salvador, and the boy and his mother met shortly afterward.

"The boy was brought in", said Eric Stover, executive director of the organization. "We explained to him that we performed the test. The mother got up and thanked everyone, then broke into tears and hugged her son. It was quite a moment."

"We sat and talked", Mr. Stover said. "We agreed that next Friday the boy will go to his mothers village and have a celebration." In a gesture of reconciliation, the boys mother, María Magdalena Ramos, asked the directors of the orphanage where her son has lived since he was a baby to come to the village and join the celebration.

Mrs. Ramos told those who helped her find her son that the child had been wrestled away by troops during a counterinsurgency sweep in May 1992 in the town of San Antonio los Ranchos in Chalatenango department, where she still lives.

The search for the boy was conducted by the Association in Search of Missing Children. The Rev. Jon Cortina, a Jesuit working in Chalatenango and one of the associations founders, described it as a grassroots organization without political or religious ties.

The organization, formed with the support of a commission set up by the United Nations mission in El Salvador after the signing of a peace treaty in 1992, has traced 13 children. It believes as many as 200 children were abducted by the

military, in circumstances reminiscent of the "children of the disappeared" in Argentina.

The second story appeared in the October 23, 1995 issue of the New York Times (Natalie Angier, "Gene Defect Tied to Violence in Male Mice"). *PResearchers at Johns Hopkins University in Baltimore have found that male mice specifically bred to lack a gene essential for the production of nitric oxide, a molecule that allows nerve cells to communicate, are relentlessly aggressive against their fellow males, often to the point of killing them.

Dr. Solomon H. Snyder and his colleagues propose that nitric oxide may normally serve as a brake on excessive and potentially dangerous behaviors, and that a lack of the chemical leads to wild, impulsive activity. The suggest the findings may have implications for understanding some forms of human aggression, although they emphasize that studies to support such a claim remain to be done.

Dr. Snyder said they planned to pursue the possibility that the nitric oxide synthase gene was involved in some small percentage of human aggression. He said it would be a relatively straightforward matter of looking at certain populations, like the mentally ill or the imprisoned, to screen for defects in the gene.

Dr. Balaban pointed out that the Johns Hopkins researchers might not realize the political hornets nest they were stepping into. He recounted the example of another recent report, cited by Dr. Snyder, which showed that an extremely rare defect in the gene for an enzyme called monoamine oxidase A caused the men of one family to become impulsively aggressive. Soon the researchers were besieged by calls from lawyers, who wanted their clients tested for the genetic defect to use as a possible defense.

These two articles illustrate the dilemma of genetic information, even in the area of nonmedical uses. In the first story, DNA tests were able to identify conclusively that the two individuals were mother and son, thereby permitting them to reunite after being separated when the boy was a young child. In the second story, on the basis of a single experiment on laboratory mice, researchers are now about to begin testing people in prisons and people with mental illness to try to prove the existence of a genetic link to violence. And what if the tests determine a link? What effect would this have on those individuals and society? I would like to briefly discuss eight broad areas in which genetic information may be used for nonmedical purposes. Each of these areas is of great concern in the United States; and from my discussions with experts from Europe, Asia, and other countries in the Americas, they also are concerns in numerous other countries.

1. Identificación. Not only can DNA techniques be used to reunite mother and son, but they can be used to identify individuals in cases of heirship. They can be used in criminal forensics to compare physical evidence in rape and murder cases with suspects, thereby including or excluding the suspect from the crime. DNA techniques also can be used to identify dead bodies, such as the remains of soldiers or victims of airplane crashes. The use of DNA data banks, such as those being collected on convicted criminals, raises questions of privacy and

confidentiality. Who should have access to these data banks and under what circumstances? What degree of quality control is necessary to ensure that a purported match is accurate?

2. Employment. There are two main ways in which genetic information may be useful to employers. First, some genetic traits make individuals more susceptible to occupational diseases. For example, alpha-1-antitrypsin deficiency, the lack of a protective serum protein, greatly increases the risk of emphysema and other lung disorders among people exposed to dusty environments. Thus, employers might want to use genetic information in assignment of employees to certain jobs. Second, in the United States, where health insurance is often related to employment, employers might be tempted to use the information contained in predictive genetic tests to try to avoid hiring individuals who are thought to be likely to develop genetic diseases in the future. Even in countries where health insurance is not dependent on employment, there are economic incentives to exclude employees who are likely to be sick in the future. These include higher absenteeism, turnover, lost productivity, and other costs. It is not clear in the United States whether discrimination against employees who are currently capable of performing the job, but who have a genetic trait that puts them at risk of future illness, constitutes unlawful discrimination based on disability. In fact, the law may differ depending on whether the individual is presymptomatic for a late-onset disorder, at increased risk of a multifactorial disorder, or the carrier of a recessive or x-linked disorder.

3. Insurance. Separate but related issues exist with regard to health and life insurance. The concern of the insurance companies is the same. Individuals who know that they are at greatest risk of illness are more likely to see to purchase the highest levels of insurance. This is referred to as "adverse selection". If these people are allowed to purchase large amounts of insurance at standard rates, the premiums would have to be raised significantly or the insurance companies will go out of business. As genetic testing becomes more commonplace in the clinical setting, it is more likely that individuals will learn of their genetic propensity to disease. If insurance applicants do not disclose test results (and if there are no records of the test results), insurers may be forced to perform their own genetic tests to ensure that there is no adverse selection. Because health insurance is viewed as a necessity in the United States, 10 states already have enacted laws that prohibit insurance companies from requiring genetic testing or denying insurance based on test results. Although life insurance is currently not viewed as being quite as important, some approaches, such as requiring insurers to offer certain small policies without any medical examinations, have been suggested as a way of promoting the economic security afforded by life insurance without the intrusion of genetic tests.

4. Commercial transactions. Any party with an economic interest in the future health status of an individual has a strong incentive to learn of the individual's genetic makeup. For example, if an individual applies for a residential mortgage with a term of 30 years, certainly the mortgage company might want to know whether the individual is going to be alive in 5 or 10 or 15 years, in order to make the mortgage payments. It is not hard to imagine that a "genetic report" along with a "credit report" may be required with a mortgage application. What are the ethical issues that this would raise, and what are the social consequences? 5. Domestic relations. There are several ways in which genetic information already has been an issue in domestic relations cases. First, in child

custody disputes, in at least one case, the husband sought to have custody of his child by arguing that because his former wife was at risk of Huntingtons disease (and had a 50 percent chance of getting the disease), she would be unable to take care of the child. Second, genetic information may be used to evaluate proposed adoptive parents in adoption proceedings. The theory is the same as in child custody disputes. Third, the most troubling use of genetics, is to test the adoptive child. When, if at all, should it be permissible to test the child and when, if at all, should adoptive parents be permitted to refuse to proceed with the adoption based on test results?

6. Education. Genetic information could be used at any stage of the educational process from elementary school to graduate school. For example, in the United States, testing for fragile X syndrome, the most common form of inherited mental retardation, already is taking in place on an experimental basis in Colorado and Georgia. Screening for dyslexia and other learning disabilities also is possible. What type of informed consent should be necessary before such testing? Who should have access to the results? What are the effects likely to be on the children, in terms of self-image and stigmatization? At the other end of the educational system is professional school. To take but one example, would it be reasonable for a medical school to refuse admission to an individual who had the gene for amyotrophic lateral sclerosis and whose medical career was likely to last, at most, only a few years?

7. Criminal justice. I have already mentioned the problems associated with identifying a gene or genes related to violence. Should the existence of such a gene constitute a defense to crime? Could this information be used by a judge to determine the individuals sentence? Could the information be used by a parole board to determine whether the individual is likely to commit another crime in the future?

8. Personal injury litigation. A number of possible legal actions may be brought against physicians for medical malpractice for failing to render medical care at a reasonable level in the use of increasingly sophisticated genetic testing and diagnosis. In addition, DNA testing already has been used to prove the cause of an individuals health problem (i.e. whether it was genetic or caused by chemical exposure). Genetic testing also may be used to determine an individuals damages in any personal injury action, by predicting the individuals life expectancy. When should a defendant have a right to genetic information and when is it permissible to introduce genetic information in court?

I have raised a number of questions, but I have supplied very few answers. For one thing, that is what law professors do. For another, the answers are still being developed, and they will vary widely based on the jurisdiction. Yet, the answers are extremely important to us all.

conclusion, all of our societies will be challenged to use the newly discovered genetic information wisely. We must ensure that the benefits are shared by all and the burdens are endured by few. It is an area in which international cooperation and understanding is extremely important, and I look forward to working with you on these issues in the months and years to come.