ISSN 2277-8721

Electronic International Interdisciplinary Research Journal (EIIRJ)
Bi-monthly Reviewed Journal May/June 2013

PRIVACY IN CASE OF MEDICAL ASSISTANCE

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Abstract

Genetic data poses unique privacy issues since it can serve as an identifier and can also convey sensitive personal information. Not only does genetic information provide a fingerprint through variations in genetic sequences; it also provides a growing amount of information about genetic diseases and predispositions.

Introduction

Errors in the genetic code are responsible for an estimated 3,000 to 4,000 hereditary diseases, including Huntington’s disease, cystic fibrosis, neurofibromatosis, Duchenne muscular dystrophy, and many others. Furthermore, altered genes are now known to play a part in cancer, heart disease, diabetes, and many other common diseases. In these more common and complex disorders, genetic alterations increase a person’s risk of developing that disorder. The disease itself results from the interaction of such genetic predispositions and environmental factors, including diet and lifestyle.

Genetic Identification

Unlike Fingerprints, DNA sequences are not unique. DNA identification works by comparing particular regions of two samples and looking for differences rather than comparing entire DNA sequences. Identification is actually a process of combining several such comparisons and calculating the probability that the two samples are a false match. “Provided that tests are actually looking at different regions of the genome, and provided that the genetic patterns aren’t ‘structured’ within a community by inbreeding, using multiple tests can reduce the chance of a false match from one in a hundred to one in a million or even one in 500 million. But they can’t entirely eliminate the chance of a false match.” That has proven to be true in at least one instance. In Britain, a DNA match between evidence left at the scene of a robbery and an individual who had already been entered into that country’s DNA database turned out to be false despite calculated odds of 37 million to one that a false match would occur. According to a FBI spokesman, “there’s a greater chance that you’ll find a close match as the databases get bigger.” Besides false matches, some criminals have become reportedly more savvy at manipulating results of DNA identification.

Genetic Testing

Advance in technology have made genetic testing easier and faster. According to genetic testing companies, kits costing USD 100 to USD 2,000 are available for over 400 diseases with hundreds more coming on the way. The easy availability of testes vastly increases the amount of information at an individual’s disposal. More problematic is the possibility that individuals will not able to control when such testing is conducted or how the results may be used. The two most controversial areas of genetic testing are in the workplace and the provision of medical and life insurance. Also, as in genetic identification, genetic testing is prone to quality control issues. A 1999 survey of genetic testing facilities found that of the 245 laboratories examined, 36 failed to meet high quality assurance standards.

Right Not to Know

While genetic screening has become easier and cheaper, treatment of genetic disease lags behind. Thus, while someone may have the ability to determine if they are at high-risk of disease, many people may choose not to find out due to the inability to take any precautionary measures. The concept of a “right not to know” would apply in these situations, allowing a person to control whether she has a certain genetic make-up. In practice, maintaining a “right not to know” can be difficult. Due to the simple inheritability of Huntington’s one family member’s decision to test herself for Huntington’s will reveal information about other family members. For example, if a daughter decides to test herself for Huntington’s due to a history of the disease through her mother's side of the family, the test results would indicate whether or not her mother also has the disease – thus compromising the mother's desire not to know.

The Patient and Right To Privacy

A patient has the right to privacy concerning his/her own medical care program. Case discussion, consultation, examination and treatment are confidential. Those not directly involved in the patients care must have the patient's permission to be present.

Confidentiality

A patient has the right to except that all communications and records pertaining to his/her care will be considered confidential, and release of such treatment information shall be only as authorized by current law and military regulations.

Information

A patient has the right to obtain from his/her physician an explanation concerning his/her diagnosis, treatment, procedures and prognosis in terms the patient can be expected to understand. When it is not medically advisable to give such information to the patient. The information should be provided to appropriate family members or, in their absence, should appropriate person. In case of the HIV positive patient; when he is going to marry a HIV negative person then it the duty of the Medical professionals or himself that he has to inform the spouse about his positiveness. Otherwise the spouse will be deceived, there is the case which we are already discussed above regarding to this e.g. Mr. 'x' v/s 'Z' Hospital.

Informing spouse or other partner

When a doctor decides to inform a third party other than a health care professional, without the patients consent, questions of conflicting moral, ethical and legal obligations arise. It is imperative that the doctor must discuss with the patient the question of informing a spouse or other sexual partner when a patient is found to be HIV positive or is diagnosed with AIDS. If the patient refuses to give consent for such disclosure, the doctor may consider informing the partner in order to safeguard such persons from infection

Medical Records

When patient have undergone tests for HIV, their doctors must maintain separate records to prevent test results from being inadvertently disclosed with other records. They can be guided by existing regulations for medical termination of pregnancy concerning the custody of consent forms and maintenance of admission registers.

Consent for testing for HIV infection. Consent may be express or implied. Express consent is an oral or written authority by the patient to render the proposed treatment. In HIV testing, written consent should be obtained. Both criminal and civil law, in particular laws relating to battery and negligence, are relevant to the legality of testing. The testing should only be performed on clinical grounds.

Pre-test counseling is essential prior to HIV antibody testing. Pre-test counseling is to be confidential and must explain the following points: ELISA test indicates the presence of a1tibodies against HIV and does not register the presence of virus itself. There is a possibility of false positive/negative results and a positive result should be confirmed by the Western blot method. The antibodies to HIV take three weeks to three months from infection to show up in the blood, known as the ‘window period’. Finally, more expensive sensitive tests such as P24 Antigen Detection and Polymerase Chain Reaction (PCR) are available which reduce the ‘window period’ to 7 days and 1 day respectively.

A particular difficulty arises when a child must be tested for HIV infection. Consent of a parent or guardian is normally sought. However, in some instances, the parent’s judgment may be distorted by the possibility that the parent may have infected the child. The parent may withhold consent to protect the parent’s own position. In such a situation, the doctor should see if the child is competent to give consent, and if so, obtain consent from the child. Otherwise, the doctor should decide whether the interest of the child should override the wishes of the parent. It is not unethical if a doctor performs such a test without parental consent provided always that the doctor is able to justify that the action was in the best interests of the patient.

Identity

A patient has the right to know, at all times, the identity, professional status, and professional credentials of health care personnel, as well as the name of the health care provider primarily responsible for his/her care.

Communication

A patient has the right of access to people outside of the hospitality means of visitors, and by verbal and written communication when such visitations and communications will not interfere with the patient's treatment

Consent

A patient has the right to receive from his/her physician information in non-clinical terms necessary to give informed consent prior to the start of any procedure or treatment. Except in emergencies, such information for informed consent should include, but not necessarily be limited to the specific procedures or treatment; the medically significant risks. Complications, and benefits involved; and the probable duration of incapacitation. When medically significant alternatives for care or treatment exist, or when the patient requests information concerning medical alternatives, the patient has the right to such information. The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his/her care or treatment. The patient has the right to refuse to participate in such research projects.

In the workplace

As DNA and genetic database become more common world-wide, there has been a concurrent rise in the use of testing by employers. Although there are legitimate uses of genetic testing, such as the prevention of occupational diseases, there is also a serious danger that employers will use these tests to discriminate against current or potential employees. Without legal intervention, information indicating, for example, whether someone is prone to a debilitating illness or even an "undesirable" condition is on as laziness or depression) may be used by employers to discriminate against employees. Despite the uncertainty about how commonly workplace genetic testing takes place, it has happened. In 1994, employees at the Lawrence Berkeley National Laboratory at the University of California – Berkeley discovered the laboratory's surreptitious practice of testing its employee blood and urine samples for syphilis, sickle cell anemia and pregnancy. The laboratory, funded by the United States department of Energy, conducts non-classified research and had been testing its employees for decades. In subsequent litigation, the government argued that since its employees had agreed to a general medical examination, they had no reason to expect that genetic testing would not also be conducted. The government also argued notice was provided via a list of tests to be conducted posted on an examining room wall. The government in the federal district court but the United States Court of Appeals for the Ninth Circuit reversed and concluded the conditions being tested for raised "the highest expectations of privacy."

Insurance

While closely tied to workplace genetic testing1, genetic testing has also begun to be used in the provision of life and medical insurance directly. Moreover, Norwich Union Life was violating the industry's code of conduct since the genetic tests had not been approved by the government's Human Genetics Commission. The controversial practice resulted in some individual's paying higher insurance premiums based on genetic predispositions, creating political pressure to outlaw the use of genetic data by insurers in the United Kingdom altogether.

Legal Safeguards

Recognizing the issues implicated in widespread genetic testing, several international bodies have recommended that genetic testing should be carefully circumscribed by law. In 1989, the European Parliament issued a resolution recommending legislation to prohibit genetic testing for the purposes of selecting workers or examining employees without their consent. It advised that employees must be informed of any analysis and implications of genetic data before tests are carried out and allowed withdraw from testing at any time. The Council of Europe has also recommended that "the admission to, or the continued exercise of...employment, should not be made dependent on the undergoing of tests or screening." Similarly, the World Medical Association (WMA) has issued statements to this effect. In Mr. 'X' v. Hospital 'Z', the Supreme Court has held that although the "right to privacy" is a fundamental right under Art.21 of the

Constitution but it is not an absolute right and restrictions can be imposed on it for the prevention of crime, disorder or protection of health or morals or protection of rights and freedom of others. In this case the appellant after obtaining the degree of MBBS in 1987 joined the Nagaland State Medical and Health Service as Assistant Surgeon Grade I.A government servant was suffering from some disease. He was advised to go to the ’Z’ hospital at Madras. The appellant was directed by the government of Nagaland to accompany the said patient to Madras for treatment. For the treatment of the disease the patient needed blood. The appellant was asked by the doctors to donate blood for the patient. When his blood samples were taken the doctors found that the appellant’s blood group was(HIV)(AIDS). In the meantime the appellant settled his marriage with one Miss ‘Y’ which was to be held on Dec. 12, 1995. But the marriage was called off on the ground that the blood test of the appellant conducted by the respondent’s hospital was found to be HIV(+). As a result of this, he contended that his prestige among his family members was damaged. The appellant field a writ petition in the High Court of Bombay for damages against the respondents on the ground that the information which was required to be secret under Medical Ethics was disclosed illegally and therefore the respondents were liable to pay damages. He conducted that the respondents were under a duty to maintain confidentiality on account of Medical Ethics formulated by the Indian Medical Council. He contended that the appellant’s “right to privacy” had been infringed by the respondents by disclosing that the appellant was HIV (+), and ‘therefore’ they are liable in damages.

A two judge division Bench of the Supreme Court comprising of Saghir Ahmad and Kripal, JJ., held that by disclosing that the appellant was suffering from AIDS the doctors had not violated the right of privacy of the appellant guaranteed by Art. 21, the Court held that although the right to privacy of privacy is a fundamental right under Art.21, but it is not an absolute right and restrictions can be imposed on it. The right to marry is an essential element of right to privacy but is not absolute. Marriage is the sacred union, legally permissible, of two healthy bodies of opposite sexes. Every system of matrimonial law provides that if a person is suffering from venereal disease in a communicable from it will be open to the other partner in the marriage to seek divorce. If a person is suffering from that disease even prior to the marriage he has no right to marry so long as he not fully cured of the decease. As such when the patient was found to be HIV (+), the disclosure by the Doctor was not volatile of either the rule of confidentially or the patient's right to privacy as the lady with whom the patient was likely to be married was saved by such disclosure or else she too would have infected with the dreadful disease if marriage had taken place.

Miss Y was entitled to enjoy all human rights available to any other human being. This is apart from, and in addition to the fundamental right available to her under Art. 21. Which guarantees right to life to every citizen of the country. Right to life of the lady with whom the patient was to marry positively includes the right to be told that a person with whom she was proposed to be married was victim of a deadly disease which was sexually communicable. Right to life includes right to lead a healthy life so as to enjoy all faculties of the human body in their prime condition. Moreover, where there is a clash of two Fundamental Right as in the instant case, namely the patient's right to privacy as part of life and his proposed wife's right to lead a healthy life which is her Fundamental Right under Art.21 the right which would advance the public morality or public interest would alone be enforced through the process of Court. The Court said that moral considerations cannot be kept bay and the judges are not expected to sit as mute structures of clay in the hall, known as Court room, but have to be sensitive, "in the sense that must keep their fingers firmly upon the pulse of the accepted morality of the day."

In Ms X v. Mr. Z, the wife filed a petition for dissolution of marriage on the ground of cruelty and adultery against husband under Section 10 of Divorce Act. The husband also asserted that his wife had adulterous affairs with one person which resulted in family way. The pregnancy of wife was terminated at all India Institute of Medical Sciences and records and slides of tabular gestation were preserved in the hospital. The husband filed an application for seeking DNA test of the said slides with a view to ascertain if the husband is the father of the foetus. The Court held that the Right to Privacy, though a fundamental right forming part of right to life enshrined under Art. 21, is not an absolute right. When the right to privacy has become a part of a public document, in that case a person cannot insist that such DNA test would infringe his or her right to privacy. The foetus was no longer a part of body and when it has been preserved in AIIMS the wife who has already discharged the same cannot claim that it affect her right of privacy. When adultery has been alleged to be one of the grounds of divorce in such circumstances the application of the husband seeking DNA test of the said slides can be allowed.

Conclusion

The prevailing scientific opinion is that most behavior and human diseases are not the result of a single mutation or gene. Rather, most facets of human development “represent the culmination of lifelong interactions between our genome and the environment.” Currently available scientific knowledge thus does not seem to provide a strong link between an individual’s genetic sequence and that perss eventual development of disease or personality traits; such conclusions are often speculative or, at best, matters of probability.

Reference

Malaka Singh v. State of Punjab, AIR 1981, SC 760

State of Maharashtra v. Prabhakar Pandurang, AIR 1986, SC 424.

Mr. ‘X’ v. Hospital ‘Z’, AIR 1995, SC 495 171 (genetic tests conducted over time to detect possible mutagenic effects of the workplace environment).

Enzyme Linked Immuno-Sorbent Assay.

the appellant’s right to privacy as part of his right to life and his prospective wife’s right to lead a healthy life, which is her fundamental right under Article 21.

k Mathiharan, Some legal and ethical implications for the medical profession

Identical twins have different fingerprints but the same DNA profiles