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Genetic Discrimination and Health Care; Ethical Reflections

by

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One can be stigmatized by society for having been diagnosed by genetic analysis with a particular disease and then denied health and life insurance when the person at that moment is perfectly capable and without a serious medical condition. Furthermore, decisions regarding prenatal diagnosis to abort because the unborn has been tested positive for a genetic disease discriminate against their right to live. Prejudice, alienation and exclusion often accompany genetic associated diseases, even though persons have no control over a disorder that is not the result of willful behavior.

1. The Human Genome Project and Genetic Discrimination

The international effort of the human genome project, which seeks to map and sequence all of the estimated 3 billion bp that make up the human genome, is expected to provide information in the near future of the thousands of mutations that are responsible for inherited diseases, thus making possible highly accurate diagnoses. The project will provide a better understanding both of single gene defects and multifactorial or familial diseases, such as diabetes and cancer.

While for some researchers the genome mapping project is essentially an engineering—morally neutral—problem, many other scientists recognize the potential ethical and sociological problems that the acquisition of the new genetic knowledge will generate. One ethical issue for consideration is the possibility of discrimination. The employer, insurer and state may have an interest in having access to information from genetic tests performed on individuals with the risk of potential genetic discrimination, such as non-equal access to work, high insurance fees and pressure to opt for sterilization in cases of carriers of genetic diseases or pregnancy termination in cases of embryos or fetuses with genetic mutations for diseases.

About 3,000 different human diseases have been shown to result from hereditary defects on a single altered gene, and many genes may play an indirect role in disease.¹ Almost 40,000 recognized disorders with a genetic component have been recorded.² Some are polygenic or multifactorial, involving the inheritance of several genes; others are monogenic, involving one gene only; others are chromosomal, involving chromosomal aberrations; many diseases result from the interaction of genes and the environment. Genetic diseases and congenital malformations occur approximately in 3-5% of all live births. It is expected that with the information generated by the human genome project, medical genetics will permeate almost every aspect of medical research and clinical practice. The number of genetic tests is expected to increase every year as a result of the information gained from the project. Genetic tests detect the mutations (changes in the genetic material) that cause the disease at the chromosomal and gene level.

Genetic Tests and Discrimination

In applying genetic tests there are complications which increase the possibility of discrimination due to misunderstandings of the implications of test results. Some of these are:

(1) Some genetic tests make possible the diagnosis of a disease before the symptoms are produced (presymptomatic diagnosis). Predictive diagnosis for late onset diseases, such as Huntington disease, is becoming increasingly possible. In this type of disease the person can live free of its effects during most of life. (2) Even when the genetic defect is present, some diseases may never be fully expressed; for example, 20 percent of persons who carry the gene for fragile-X, the most common form of mental retardation, never express any form of mental retardation. (3) Though genetic tests for susceptibility to certain diseases, such as for coronary heart disease and cancer, will be developed, these can only provide probabilistic information whether an increased risk exists. (4) Errors in the diagnosis depending on the disease, the type of mutation, and the test employed may also occur. Indeed, differentiation between harmless polymorphic alterations and disease-causing mutations is difficult without the additional work of sequencing, which is not always feasible. In the case of a test for detecting a polymorphism in a nearby region of the mutated gene, which is inherited with the disease, there is the chance, although slight, of genetic recombination which yields false results. (5) For many of the diseases there is genetic heterogeneity so that more than one mutation and/or gene are involved; particularly X-linked diseases are prone to newly arising mutations so that almost every affected family displays a different alteration. Testing for the large number of mutations that may be involved is usually not feasible and it can lead to misdiagnosis if the particular mutation causing the disease is not covered by the test. (6) Even with the same mutations in some cases (susceptibility-conferring mutation) there are markedly variable clinical expressions depending on environmental factors and modifying genes that interact with the mutated gene. (7) Even when a particular disease can be diagnosed, in many cases there is no cure for it. (8) The process of explaining genetic risks is complex and easily misunderstood by people without a background

in genetics. Genetic counselors and doctors and nurses with adequate background in genetics are necessary. (9) It will take time until a consensus is reached by the medical community about which genetic tests have sufficient predictive value for specific diseases.³

With the new information generated by the genome project the probability of finding mutant genes is going to be greatly magnified, so that the possibilities of being stigmatized will be much greater.

3. Genetic Discrimination and Health Insurance

One potential risk of genetic discrimination, based on the acquisition of information through genetic tests, is in relation to the insurance industry. Insurance companies can discriminate by denying life, health or disability insurance to people on the basis of their genotypes. The current health-care system in the United States focuses on treatment rather than on prevention. For that reason, the predictive value of genetic tests is of little positive value for insurance companies. But, health insurance companies, in order to keep their prices down and to be competitive with other companies, may refuse to insure people who are at risk of having high medical expenses. As a result, some people cannot afford insurance because they are already ill or are at risk of illness. Through the principles of underwriting, insurers estimate the chances that an applicant will make a claim. The notion of "actuarial fairness" plays a key role in this estimation. By means of it, parties seeking insurance ought to pay according to their potential risks for filing a claim. Many insurance companies require physical examinations which sometimes reveal genetic disorders, and ask questions of the applicants which may elicit information about their genetic background. Applicants are also asked to permit release of medical information from doctors who previously have treated them. There are no safeguards to prevent insurance companies from exchanging stigmatizing information with employers during the claim process. During underwriting, physicians commonly release genetic information to insurers.⁴

At present it appears that insurance companies do not require molecular genetic tests in underwriting or in the process of establishing premiums according to the risk of developing diseases. Still, insurers make decisions based on genetic information, including family history or prior diagnostic tests performed on the client or his/her family. Many companies require policyholders to sign releases that allow access to any and all records. Currently most genetic information available is too costly to be used as a routine insurance screen. However, with technological advances it is expected that genetic testing will be included in insurance underwriting in the near future by using cost-effective multiple tests. The common, severe and costly diseases are most likely to attract insurers' interest once the predictive value of a genetic test is confirmed and the word spreads among insurers. Biotechnology firms are interested in developing diagnostic tests for genetic disorders and one potential market for the use of these tests is the insurance industry.⁵ Insurers insist that they must not be prevented from using data on genetic-testing already collected in the medical record to assess risk of candidates for initial coverage in order to protect the companies and other policyholders from

the results of adverse selection.⁶

Adverse selection consists in the tendency of people who learn they have higher risks of disease to purchase insurance. This occurs when individuals have more information about their risk of illness than do insurance companies. Adverse selection poses a greater problem to insurance companies for life and disability insurance since these forms of insurance are obtained through individual applications. Insurance companies claim that adverse selection will jeopardize their interests and for that reason they are developing strategies to protect themselves. Because of competition among insurance companies, the tendency will be towards screening for predisposition. If one insurance company begins to use genetic tests and is able to offer lower rates to individuals who are not predisposed to disease and higher rates to individuals who have predisposition to disease, this particular insurance company would draw people who are offered low rates and this will put pressure on other insurance companies to also offer genetic tests. In this way insurers can assess the risk of candidates for initial coverage, their renewal or increased coverage or decide not to cover certain individuals.⁷

On the other hand, the health insurance industry has been criticized for practicing "adverse selection," for example, by discontinuing coverage when a client, who has been faithfully paying premiums, is found to have a serious condition.⁸ The proliferation of new genetic tests heightens the concern that insurance companies, requiring applicants to provide blood samples, may perform genetic tests on them without making the results known to the clients.⁹ In the absence of a cure for most genetic diseases, insurers will be reluctant to insure people at risk of developing costly disorders. This issue provides a high potential for discriminatory practices.

4. Genetic Discrimination and Abortion

Genetic discrimination may result in the abortion of an individual who tests positive for a genetic disease by prenatal diagnosis, although every human being -including fetuses - has the right to receive adequate medical attention if needed. The possibility that insurance companies will refuse in the future to insure individuals who, as fetuses are shown to have a genetically inherited disease, will put pressure on families to abort because of economical constraints. Furthermore, if abortion of genetically defective embryos or fetuses becomes widespread, there is the danger of reinforcing negative attitudes in society against people born with disabilities. Theoretically, for single gene disorders for which there is no present cure, to try to develop gene therapy constitutes an alternative. In reality, however, the impetus for developing this therapy is blunted by the use of gene probes and other diagnostic technologies to detect and abort affected fetuses and to counsel at-risk adults against procreation. Furthermore, the practice of embryo selection in *in vitro* fertilization procedures is as well discriminatory, since the embryos not selected are very rarely given the chance to develop.

5. Ethical Reflection

I consider that ethical reflection needs a proper definition of personhood on which to base moral decisions. For example, moral decisions with respect to the implementation of genetic knowledge depend on the value given to the person as a whole. In a society where there is confusion over what it means to be a person, there is also a confusion over what is moral. It is then necessary to consider the definition of personhood in accordance with the dignity due to a human being. Genesis (1:26) gives a transcendental meaning of what a human being is, revealing that he/she is "image and likeness" of the Divine being. Through the motif of the image of God (cf. Ps 8:5; Wis 2:23; 1Cor 11:7) the Bible affirms the sacredness and dignity of every human person. According to Gula this statement contains the theological meaning that God has established a relationship with human persons which is sustained by divine faithfulness and love.¹⁰ The statement also contains the anthropological meaning that we all share a common human condition with God as common end, and that human dignity does not depend on human achievements alone, but on divine love as well. For the contemporary philosopher Fernando Rielo this statement implies that the Divine being is forming ontologically the human being.¹¹ Personhood cannot be defined by something inferior to itself. To assert this would be to reduce the person to a property, such as intellectual capacity, independence, etc. Rather, personhood should be defined by a term, the Absolute being, that transcends and encompasses all these characteristics. The essence of the human person is to be a being in relation to God, thereby to other human beings and to the whole of nature. This definition renders morally prohibitive any action that would in any way compromise the proper realization of this relationship. Faith helps Christians to see the dignity of a human being against cultural pressures that distort it. The capacity of the human being to establish human rights and the ethical obligation to carry them out confirms that the person cannot be reduced to a naive or moderate materialism.

The Magisterium has consistently taught the dignity of human beings and the inviolability of human life. Human dignity, rooted in the Bible, arises from three sources: creation in the image of God (Gen. 1:26), redemption, achieved through the incarnation, death and resurrection of Jesus Christ (Jn 3:16; Eph 1:10; 1 Tim 2:4-6), and our common destiny to share a life with God beyond all corruption (1 Cor 15:42-57; 1 Jn 3:1-2).¹² When the Magisterium asserts that human life is sacred, given that from the beginnings it involves "the creative action of God and it remains forever in a special relationship with the Creator, who is its sole end,"¹³ and that "the spiritual soul of each man is immediately created by God",¹⁴ it is arguing that there is no separation between the spiritual dimension of the person and the individual's physical life, since both are present from the beginning. Human life therefore is sacred; it has been touched by God and deserves the highest respect from the moment of conception.

Morally every individual should be given the highest value regardless of race, ethnicity, social condition, age, sex, stage of embryonic or fetal development, religion or physical health. All human beings deserve respect and protection and

promotion of their basic rights because of their dignity. The value of a person cannot be measured by his/her genetic constitution. Knowledge of the genetic cause of diseases has as its final objective the cure or prevention of the disease, not the elimination or discrimination of the individuals that possess genetic mutations. Virtually all human beings possess one or another genetic mutation. The fact that one has mutations does not necessarily mean that this is an evil. Part of the function of mutations is an evolutionary strategy to provide a reservoir for adapting to changing environmental circumstances. Performing genetic testing for the purpose of eliminating the individuals that do not test normal is clearly immoral. Choosing embryos with a particular genotype in in vitro fertilization procedures is immoral because it implies making a judgment regarding which embryo deserves to be developed and which one does not; ultimately this is a value judgment concerning who has the right to live and who does not. The embryos which are not destined to grow must be frozen, destroyed or used for research, which clearly violates human dignity.

Performing genetic tests with the purpose of identifying individuals who do not test normal and then denying them insurance or other basic values is immoral because it violates the right to receive health benefits. This goes against justice. I consider that the practice of establishing premiums based on risk by insurers is unjust and therefore a better system must be found. The notion of actuarial fairness does not coincide with moral fairness. The expenses of health care should be shared by all equally with the establishment of adequate social policies. It is not right that because somebody has been born with a genetic disease, he/she has to pay more. This puts pressure on families to avoid having a defective child and leaves society with the impression that it is better not to care for those who have abnormalities. We are here in life to help others, not to put further difficulties on those who have been born with health problems. The present health care system in the US does not promote equal opportunity since access to health care depends, for the most part, on the ability to pay. The health care system should reject the possibility that individuals can have economic advantage from differences in their health risk. On the other hand, enhancement services, such as "cosmetic surgery," could be excluded from coverage on the ground that it does not constitute a treatment of disease and there is no social obligation for it.

Conclusion

Maximum respect for human dignity should be the guiding principle in all ethical decisions. If the person is an "image" of God, then maximum respect and treatment should be given to the person, without discrimination, regardless of race, ethnicity, genetic constitution or stage of development. Laws that permit abortion or active euthanasia go against human dignity. Health is not an absolute end, but a subordinate goal; thus it is not the case that if you are not going to be healthy, it is better that you do not live; rather, health is a means for improving the quality of life for which we strive. It is necessary to emphasize the value and the importance of every human being.

A reform in the health care system in this country could prevent the possibility

of genetic discrimination by insurance companies by assuring access to care for everyone. At present the law does not seem to prevent insurers from exercising genetic discrimination. The general applicability of genetic tests may force the situation in the direction of socialized medicine, which will be more effective in handling the problem. This is critical for cases of (1) presymptomatic diagnosis in which the patient is at risk of having high insurance premiums in the present system instead of receiving preventive care, and (2) for prenatal diagnosis of diseases for which there is no cure.

Abortion for fetal indications is immoral because it involves the end of a life, when life constitutes a higher value than the suffering a human being will have to undergo if genetically injured. Society has the duty to try to provide the best environment possible to diminish the suffering of individuals born with diseases. If there are no institutions that care and help individuals with genetic diseases, all the burden falls on family members who are pressured to avoid the birth of these individuals. Hence the development of needed services and institutions is clearly a societal responsibility.

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