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Social Attitudes and the Human Genome Project: Ethical Implications

by

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The international effort of the Human Genome Project (HGP), 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 on 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 or cancer. There is a great potential for the possibility of improving the length and the quality of life and probably in reducing costs in health care by introducing new, less expensive and more accurate tests. It has been estimated that detailed mapping may be completed in 10 years and that genetic testing and the possibility of genetic manipulation will become available for a variety of purposes.

While for some researchers the genome mapping project is essentially an engineering – morally neutral – problem, many others recognize the potential ethical and sociological problems that the acquisition of the new genetic knowledge will generate. While it is recognized that knowledge in advance of diseases allows those so affected to minimize their effects by altering unhealthy lifestyles, choosing health enhancing diets and/or environments, taking appropriate medications and deciding whether or not to parent when at risk of having genetically damaged children, there are

considerable ethical and sociological issues associated with such knowledge.

We are entering a new era of bioethical reflection, in which issues are being discussed at an international level. There is worldwide recognition that the very essence of human nature needs to be protected. Molecular biologists, philosophers, ethicists, theologians, physicians, sociologists, anthropologists, lawyers and educators are called to interact in discussing the numerous implications of the project.

The knowledge developed through the HGP is expected to generate medical and social applications in the areas of 1) Genetic testing and screening for disease-causing mutations; and 2) Genetic engineering with the development of gene therapy and genetic enhancement techniques.

I. Genetic Testing and Screening

Workplace genetic screening was first justified by its consequences for public health by Haldane.¹ He postulated that the difference in response to toxic exposure could be genetically determined and that individuals who are genetically susceptible could be placed in different occupations. Haldane's rationale was revived in the 1960s and 1970s with suggestions that new screening techniques might make it possible to put his idea into practice.² Presently the technology for genetic screening has been refined, and it will be possible to expand the same with the information gathered through the genome project. In the same way, insurance companies are interested in developing genetic tests to evaluate the probability of filing claims by applicants for health insurance and thus enable them to establish their premiums.

The State as well has an interest in technologies that will reduce the hardships brought about by disease. Particularly tests for diseases of high incidence, whose care is costly in the absence of predictive testing and for which the costs of screening and subsequent interventions are relatively small, are quick to receive government support and qualify for state-sponsored mandatory screening.

HGP is expected to generate tests for both symptomatic and asymptomatic individuals. The decision to be tested by genetic tests requires informed consent by potential testees, especially because there may be associated problems which arise from the information obtained.

Some of these problems are:

First: There is a substantial risk for social stigmatization with positive results from genetic tests. To change a faulty gene is not possible

in most cases, so that when a person is tested for one of the known genetic diseases, he/she is automatically labelled with the disease and this is perceived as an immutable fact. This is aggravated by the fact that in the popular mind genes are considered emissaries of biological destiny. The fact that genetic expression is often affected by interaction with environmental forces has not clicked in the popular understanding.

Second: If the test is made mandatory or the person is pressured to take it, this will affect the possibility of exercising autonomous decisions. An example is when women are pressured to undergo genetic tests to obtain information about genetic abnormalities present in the embryo or fetus they carry with the intention of favoring abortion.

Third: When treatment of the disease being tested is expensive, there is risk of discrimination by insurance companies and employers, like insurers charging higher premiums and employers avoiding the hiring of persons for whom there will be high medical expenses.

Fourth: For multifactorial disorders, tests have little predictive value since both the environment and genetics interact in many possible ways to cause the disease in several possible degrees, which is not easy for some to comprehend.

Fifth: When there is no effective method for prevention or treatment of a disease, the disclosure to a patient that he/she has the disease may cause serious emotional and ethical difficulties. This has been the experience reported for Huntington's disease, which is an inherited disease that is manifested in late life. The knowledge of testing positive for the disease has had an enormous psychological impact on many individuals increasing their anxiety, in a few even leading to suicide attempts.³

The issue of mandatory screening is complex and should be carefully considered. Each disease has its own complications such that before making any decisions the ethical implications need to be taken into account. Population screening may be beneficial in some cases for genetic susceptibility to serious diseases when preventive measures and therapeutic approaches are effective, but this should be introduced only cautiously, with safeguards, and after careful clinical and psychosocial evaluations of pilot programs have shown that there is a direct benefit in preventing the acquisition of the symptoms of the disease. Its implementation requires that, in order to guard against possible abuses, leaders from the communities affected, without vested interests, should participate in the decision to implement policies for screening.

Caution must be taken since there is concern that mass screening programs may be driven by political considerations or a desire for profit. For example, a major factor in the federal funding of sickle cell screening

was a political promise by President Nixon, who expected political support from African-American leaders. Physicians and community leaders were attracted by the project because of the availability of money.⁴ The results of this screening program were disastrous. There was no appropriate counseling provided, people were psychologically harmed by the information, and societal institutions did not know how to use the test results, which were used to discriminate against the individual carriers of the disease in insurance and employment.⁵

II. Genetic Engineering

Through recombinant DNA technology, scientists are able to alter the genetic material of organisms by introducing foreign DNA of the same or different species. Genetic engineering has developed a new type of therapy which consists in replacing a mutated gene or adding a normal gene capable of producing the desired or normal product, thereby targeting directly the cause of the defect. There are two different categories: (a) germ-line therapy, which consists in interventions that involve the human germ (sex) cells; and (b) somatic cell gene therapy, which consists in interventions in any other cell of the adult body. Somatic cell therapy has been under way since 1990, but germ-line therapy has not yet been attempted. Technically, germ-line gene therapy is more difficult than its somatic counterpart, since it must be shown that the inserted gene will not cause adverse developmental effects.

The use of germ-line genetic alterations has been suggested for the prevention of disease in future individuals by introducing normal DNA into the gametes or by exerting the genetic alteration in a zygote at an early stage of development before the process of cell differentiation and the development of body organs.⁶ At an early stage the genetic change will affect all the organs and tissues, including the germ-line of the adult that develops. The zygote is accessible to genetic alterations in conjunction with *in vitro* fertilization procedures. However, the claim is that the germ-line gene therapy option in the zygote will be rarely taken when there is the simpler and less risky option of not transferring preimplanted zygotes that are tested as having a genetic anomaly (embryo selection).⁷ This is done by removing one cell from an embryo created *in vitro* and using gene amplification techniques to produce enough DNA for analysis. The embryo, free from mutation, is the one used for implantation.

Non-therapeutic genetic alterations in human beings are also possible by attempting to enhance the healthy genetic makeup of an individual by inserting a gene that improves certain qualities, such as beauty, intelligence, and longevity.⁸ This is called genetic engineering

enhancement. Today we do not have the technical means to induce such alterations, but it is possible that with the information generated by the genome project some of these change may be more accessible.

III. Social Aptitudes

In today's cultural environment in the US, freedom and autonomy are estimated as the highest values, together with pleasure, efficiency and consumerism.⁹ When freedom is absolutized, many unethical attitudes and actions are justified. When autonomy is absolutized, there is no room for social solidarity and service to others. The dominant culture promotes individualism, in which the person exists apart from others and serves to promote ideas of personal freedom, self-improvement, privacy, achievement, independence, detachment and self-interest.¹⁰ There is a crisis in interpersonal relationships, which results in weakening community bonds. Furthermore, there is a growing skepticism in relation to the possibility of having a valid ethical foundation and moral uncertainty prevails.

Today's society is excessively concerned with efficiency and functionality.¹¹ Most people adopt utilitarian attitudes with everything in life including issues related to human dignity, in which only what is useful is accepted. Under the utilitarian conception only what works is good. This leaves little room for compassion and acceptance of malformation in individuals. Because of the tendency in today's society to hedonism, human suffering is considered an evil that must be avoided. Suffering has no meaning for most people today. With this attitude, the danger is that anyone who is handicapped or is affected by illness or any limitation may be considered as one which should not have been given the gift of life. Many people believe that it is better to be dead than to live a life in pain or as a handicapped person, or to suffer from mental illness. A result of this mentality is the increase in the health care system of claims of "wrongful birth" and "wrongful life."¹²

Another factor that influences the decisions that people make is the prevalence in today's society of an interventionist mentality in which whatever is possible for technology to do is considered good without entering into a critical ethical assessment. Techniques such as genetic enhancement may be considered justified in the future as long as they are technically feasible. As improvements in techniques are made public, the probability of societal acceptance increases. In a recent poll carried out by the March of Dimes, forty-three percent of respondents said that they would approve using genetic technologies to improve the physical

characteristics of their children or their intelligence if the technique becomes available.¹³

Also, present-day culture is evermore predisposed to accept genetic explanations by media coverage. Genealogies and the search for roots are becoming increasingly popular. There is a growing preoccupation with identifying the genetic characteristics of specific societal groups and even fear that human beings are threatened with evolutionary decline. The genetic basis for alcoholism, crime and other social illnesses is being treated by media with increased interest. As a result, many people believe that all traits, behavioral as well as physical, are genetically predetermined. This has the effect of deemphasizing the important role of psychosocial and cultural factors. With this type of mentality, the ones that are going to be more affected are the weakest in society. People may start to abort fetuses that carry genes that have been associated with societal maladies, such as aggressivity, while little is done to improve the sociocultural conditions that lead to aggressivity. Children may be more vulnerable to genetic labeling and be subjected to stigmatization or discrimination.¹⁴ Being inappropriately labeled as sick or abnormal may undermine the children's capabilities to grow as persons.

In the health care system, consumerism has invaded the field of medicine, so that health care delivery is envisioned under the umbrella of consumer rights and consumer protection. As a consequence, a "malpractice mentality" has been developed in which physicians are expected to carry out their professional responsibilities with a high degree of competence, so that from even a minor mistake, patients have the right to file a lawsuit.

Due to the commercialization mentality in the US, genetic testing services have begun to move from academic medical centers to the private enterprise arena. Substantial motivation exists to encourage DNA testing to enter the marketplace as soon as possible. New commercial testing laboratories have been created in conjunction with academic medical/molecular genetic researches, and prior major diagnostic companies are developing genetic technology in the hope that genetic tests will be shortly adopted as standard medical practice, for which there will be a major diagnostic market potential.¹⁵ It is expected that marketing efforts will be directed not only to the practicing physicians, but also to the general public, through extensive advertising, encouraging prospective patients to ask their physicians for certain genetic tests.

There is a danger that, because of the consumerist, interventionist, and utilitarian mentality added to the new genetic knowledge, people will start seeing themselves just as an assemblage of molecules controlled by genes. As products that can be manufactured and subjected to quality

control measures, embryos might be manipulated. Children might be considered products, and thus actions could come to be considered genetically determined rather than the result of free will. These concepts can undermine human dignity and negate human freedom.

IV. Ethical Reflection

Due to the prevalence of freedom and autonomy as highest values in the dominant culture, today's society lives a moral relativism which is translated into a pluralism of opinions and behaviors; decisions depend on the system and hierarchization of values given by the individual or by the multiple groups in society.

Society needs to reach a consensus in which to base ethical reflection. Any consensus that would be reached must be founded on the dignity of human beings, which resides on its essence. The human being as person should be the center of morality. If an adequate understanding of personhood, in accordance with human dignity, is not given, all moral systems fail in helping to humanize society. If the value of a person is relativized, the ethics and rules of society fall victim to relativism and subjectivism. Maximum respect for human dignity should be the guiding principle in all ethical decisions, irrespective of religion or culture. For us, Catholics, the Magisterium has defined human life as sacred since conception, endowed with dignity through the creative action of God.¹⁶ This sacredness can also be envisioned rationally. Fernando Rielo, a contemporary philosopher, has shown that it is rational that human personhood can not be defined by itself or by one of its properties or capacities, rather human personhood must be defined by something superior, what Rielo calls the constitutive presence of the absolute subject.¹⁷ Since this definition provides a foundation to human dignity I take it as a starting point for any ethical reflection.

Considering the dignity of a human being and his/her relational character, as a being created through an action of love, the following moral principles should not be violated in the application of the genetic knowledge derived from HGP:

1) Protection of life. Human life is sacred. This demands reverential attitudes and practices in the exercise of genetic science, trying to preserve life rather than putting it at risk or destroying it. Human life is a basic gift and good, the foundation of all other goods.

2) Beneficence and nonmaleficence, by promoting good and avoiding and preventing evil. This, however, does not mean that causing certain disvalues as a second effect makes the action morally wrong.

3) Justice, which demands the avoidance of discrimination and the moral distribution of goods. There is no difference by which one human being has more inherent essential or radical dignity than another. We also need to exercise distributive justice in the priorities of genetic research and the enjoyment of its benefits. The disadvantaged require greater consideration under the demand to love those that do not have. Justice is tempered by love.

4) Respect for personal autonomy, based on personal freedom, acknowledges that each competent adult has primary responsibility for personal health care decisions. This principle must also be shaped by love. Personal freedom is limited by the freedom of the others.

These ethical principles shaped by love provide sufficient basis for an evaluation of the ethical issues resulting from the application of genetic knowledge as follows:

a) Genetic Testing and Screening

Informed consent to undergo genetic testing and to follow treatment must always be assured with adequate counseling based on the moral principle of respect for personal autonomy. No consent, however, should be given to research on new forms of therapy or genetic screening that goes against human dignity, for example, donating embryos for the purpose of doing research on them. Also, diminishing the capacity of persons to make personal decisions to make personal decisions by pressuring or forcing them goes against personal freedom and therefore human dignity. Mandatory screening could be introduced cautiously only when it has been demonstrated to be for the overall benefit of the individual and of the community and not against the principles of justice and the preservation of life. 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. Those that are in favor of abortion in this case invoke the principle of nonmaleficence, but there is no life without some kind of suffering and therefore the elimination of suffering can not be the basis for not allowing somebody to develop. At the same time, society has the duty to try to provide the best environment possible to diminish the suffering of individuals born with diseases, thus exercising compassion and care, which forms human character and gives a value to the suffering of those individuals. 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. The Magisterium asserts the rights of patients to be fully informed¹⁸ and

condemns discrimination¹⁹ and abortion, including those done for therapeutic reasons and selective abortion in order to prevent the birth of children affected by various types of anomalies.²⁰

b) Genetic Engineering

Gene therapy can be considered an innovative form of therapy, as part of the medical progress to cure diseases. Somatic gene therapy can be considered moral because its aim is to cure an already existing disease. Somatic gene therapy raises no other ethical issue than that arising from technical advancement, if the technique is sufficiently tested so that benefits outweigh the probable risks. In the case of germ-line therapy, the objection has been made that it violates human dignity because it changes the genetic content of subsequent generations whose consent can not be obtained and whose best interests would be difficult to calculate.²⁰ However, this is not the main ethical issue. The decision to perform germ-line therapy could be moral when its aim is to prevent human suffering and premature death, since these are universal aims for any human being, and hence do not require previous informed consent. But in the present stage of technology, to perform germ-line therapy violates human dignity since it risks damage to future generations.

With respect to genetic enhancement one of the problems is that not everybody agrees on which characteristics are considered favorable. Considering the utilitarian outlook of the dominant culture, a societal acceptance of genetic enhancement will most likely lead to discrimination and to the devaluation of certain categories of people whose genes are not considered worthy of imitating. There are no objective criteria, free from prejudices, that can establish which qualities of human beings are better than others. If new abilities are developed through genetic enhancement, the unenhanced normal level may be seen less significant as a standard by which to measure ourselves and our own abilities. This, in turn, may have adverse effects in causing, for instance, insecurity in those so affected in developing a sense of self-respect. Furthermore, genes and their products have a relative value. Today's environmental conditions may change in the future and what is estimated as good today may not be so in the future.

For some philosophers there is no moral basis for restraining human beings from altering their nature. When the possibility of such alterations arrives through genetic technology, this needs to be regarded as a ground for setting aside many of the hindrances of our biological makeup in order to realize our goals as persons.²² LeRoy Walters has advised that "we should not lose sight of the potential contribution of gene-mediated enhancement to the welfare of the human race."²³ Directed genetic

enhancement could be beneficial for individuals and for the entire society once the technology is available. Examples of these are 1) improving the body's immune system for resistance to infections and cancer, 2) reducing the body's need for sleep without loss of attentiveness during waking hours, 3) increasing the power of memory, 4) reducing aggressive tendencies while increasing generous and peaceful ones, 5) delaying the effects of aging and prolonging the span of human life.²⁴ In fact there is a fine line that separates enhancement from illness or prevention to improve the body's defenses against disease. There is a need therefore to define these limits. Another problem is that these proposed enhancements could all have serious negative unintended consequences under the present stage of technology.

However, under the ethical perspective, genetic manipulations performed on embryos are not justified unless they are for therapeutic reasons, considering the moral principles of justice. All types of genetic manipulations which aim to modify genes for what society considers nontherapeutic purposes are immoral since their aim is to enhance particular human traits that have little or nothing to do with disease, such as beauty or the ability to develop particular skills, thus making a judgment over which traits are superior to the detriment of people who do not possess them. Those endowed with superior traits would most probably be considered isolated from the rest through the diminishment of others. Any diminishment of the human being goes against human dignity as is immoral. Society, however, may accept as therapeutic some of the proposals given above by LeRoy Walters if they are related to the health of the individual. Prevention can be considered therapeutic when there is risk of acquiring particular diseases. Decisions in this line will require careful reflection involving scientists, physicians, philosophers and theologians. Only therapeutic genetic manipulations are morally justified, but not the manipulations done with the view of enhancement. The Magisterium has condemned nontherapeutic genetic manipulations.²⁵ On the other hand, Pope John Paul II has given words of support and approval of somatic gene therapy as long as human dignity is respected.²⁶

Conclusions

Some of the social attitudes of the dominant culture may make the applications of genetic knowledge gained through HGP go to the detriment of human dignity. I conclude that it is necessary to provide an ethical foundation on a definition of personhood on which human dignity can be founded. Furthermore, society has the responsibility to educate people on strong moral foundations so that the difficulty of ethical reflection is

minimized and does not become a burden due to subjectivism and relativism. We, Catholic educators, have a responsibility to shape a Christian culture in which ethical reflection is made in accordance with the preservation of human dignity. We also need to present Christian understanding in a way that will influence the popular culture.

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