Genetics and Social Policy

GENETİK VE SOSYAL POLİTİKA

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Summary

Genetics and its social problems are important subjects of today. In the United States, legislators have focused on barring genetic discrimination in health insurance and employment, and on protecting genetic privacy in order to prevent discrimination. In this article, some samples are given and some scientific results are obtained about these subjects.

Key Words: Genetics, Social policy

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Özet

Genetik ve onunla ilgili sosyal problemler bugünün önemli konularıdırlar. Amerika Birleşik Devletleri'nde, kanun yapıcı idareciler sağlık sigortasmdaki genetik ayırımı önleyici ve gizliliği koruyucu yasalara yöneldiler. Bu çalışmada bu konuda bazı örnekler verilir ve bazı bilimsel sonuçlar elde edilir.

Anahtar Kelimeler: Genetik, Sosyal politika

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To resolve the social and ethical issues raised by advances in human genetics, policy makers must balance the interests of public health, genetic scientists, human research subjects, biotechnology firms, and nonmedical users of genetic information, such as employers and insurers. Balancing these interests, which are often in conflict, may lead to different results in countries with different cultures and economies, particularly when most of the social problems associated with genetics have not yet been experienced. Our effort here will not be to recommend specific resolutions of the anticipated issues, but to suggest how policy makers in Turkey might approach this area.

Human genetics raises ethical and social issues because the science can involve or lead to discrimination in insurance and employment, stigma and intrusion on personal freedom, misuse of human research subjects, and widening of the gap in health care provided to rich and poor. Genetics is not currently a significant cause of these problems. Concern for the future, not actual difficulties experienced by individuals, has promoted the adoption of laws and conventions on nonmedical uses of human genetics.

In the United States, legislators have focused on barring genetic discrimination in health insurance and employment, and on protecting genetic privacy as a means to prevent discrimination. Although federal legislation on such matters is limited, half the states have prohibited genetic discrimination by health insurers, and a third of the states have prohibited genetic discrimination by employers. This legislation might seem a substancial accomplishment, but it regulates nonexistent problems and therefore may have little impact.

Three-quarters of the United States population has health insurance funded by employers or the government. This coverage is provided to all who qualify, without regard to genetic characteristics or any other indicator of an individual's health status. Only seven percent of the United States population purchases individual health coverage, and the chief reason for denying this coverage is actual experi-

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ence, not genetic prediction, of medical treatment. The absence of health coverage for fifteen percent of the United States population - over 40 million people - is due to lack of affordability, reduced subsidization of health insurance by employers, reduced welfare benefits, and, of course, the failure of Congress to provide free universal coverage. There is no evidence that genetic discrimination by health insurers has contributed significantly, if at all, to lack of coverage.

Similarly, there is little evidence of genetic discrimination in employment, because employers in the United States conduct very little genetic testing. Surveys by the Office of Technology Assessment (1990) and the American Management Association (1998) indicate very few employers, probably well under one percent, conduct genetic testing. Since the state laws barring genetic discrimination by employers are recent, lack of economic justification has had more effect than the laws in discouraging testing by employers.

With so little evidence of genetic discrimination in the United States, the introduction of many bills in Congress and the adoption of laws on this subject by the majority of states seem a disproportionate response to a minor problem, even if the legislation is intended to anticipate greater difficulties in the future.

There are several reasons for the flurry of genetic anti-discrimination legislation, some peculiar to the United States political scene, others of broader significance. The genetic anti-discrimination laws in the United States attempt, in a small way, to counteract a frustrating political inability to adopt universal health care. If the United States provided free health care to all, there would be no need to prohibit genetic discrimination in health insurance. Also, there would be less need to prohibit genetic discrimination in employment, since the main incentive for employers to discrimination on the basis of genetic characteristics is to limit the cost of employer-provided health coverage. Thus, the absence of universal health coverage creates the apparent, if not real, need for genetic anti-discrimination laws in the United States.

The legislative concern about genetic discrimination also reflects the popular presumption of equal opportunity for all. Genetics may challenge this presumption by providing a new kind of difference that can be used to discrimination among individuals. Commenting on the publicly funded Human Genome Program, United States Congressman David Obey stated, "It would be a tragedy ... if those dollars, instead of winding up producing a net good for the American people, wind up simply producing a greater ability for different powerful parties in this economy to discriminate on the basis of genes which individuals could not order beforehand but were stuck with after they were born." Human experience includes too many examples of discrimination based on race, ethnicity and gender, and we are naturally cautious when science discovers a new difference that can be used as a basis for unfair treatment. The challenge is to use genetic difference in ways that benefit individuals, not mark them apart to their disadvantage.

Although well-intentioned, the emphasis on genetic issues may foster an atmosphere of genetic determinism and reductionism that can lead to neglect of the environmental causes of problems and diversion of scarce resources. Traditional methods of improving social conditions may be ignored in favor of tinkering with the genome. Genetics is an expensive, "high tech" endeavor that can benefit a few persons at the cost of providing basic health care to many more individuals. Thus, the problems associated with genetics reflect broader issues faced by a society. Genetics may aggravate a lack of access to health care due to budget constraints, or lack of protection of medical information, or failure to prevent discrimination.

Policy makers should determine which social issues raised by advances in human genetic require immediate attention and then consider the policy alternatives to deal with the most pressing issues. Genetic discrimination and loss of genetic privacy are probably not significant problems in Turkey today, no more so than in the United States. Consequently, genetic privacy and anti-discrimination measures may not be a top priority. A more immediate concern about genetics in Turkey is the conduct of genetic research in a manner that will achieve scientific and medical goals without violating the rights of human subjects who donate DNA. In this area, the small country of Iceland may provide the most useful model of policies to follow or avoid.

The issue of human subject protection is often reduced to the challenge of obtaining informed consent from unsophisticated persons who find the complexities of genetics and the risks from participating in genetic research difficult to comprehend. However, informed consent does not require complete understanding of the research and all possible consequences. It does require the researcher to make an honest attempt to overcome disparities in knowledge. Using everyday language, the researcher should inform prospective subjects about the nature of the research, the possible benefits, and the risks from participating as a subject. Informed consent is an educational as well as a deliberative process. The goal is to enable human subjects to be true participants, not mere objects of the research.

Informed consent is not the sole condition for the ethical conduct of research with human subjects. A researcher (or policy or ethics body) must first determine whether participation of human subjects is ethical under any circumstances. Is there sufficient justification to expose human subjects to risk, even if the risk is minor and the subjects are willing to participate? This inquiry requires consideration not only of risks and benefits to the human subjects, but also broader issues, such as the benefit, if any, to society from the use of individuals as human subjects.

Human subjects are seldom rewarded by direct payment for donating biological samples. Customarily, subjects benefit only indirectly, by assisting an effort to learn about, and ultimately to treat or prevent, disorders they may inherit. The subjects themselves may benefit from this scientific advance in the future, but that possibility is usually too remote to be considered a significant benefit from their participation in the research.

The risks to donors of biological samples arise largely from the potential disclosure and misuse of the genetic information gained about them. Some problems, such as the identification of false paternity as a byproduct of genetic testing, can be foreseen and their consequences largely avoided by such measures as advance warning to potential research subjects and non-disclosure or camouflage of test results. Similarly, the risks from potential uses of research information to discriminate can be avoided by measures to protect identified research data from disclosure.

Other issues may be more difficult to resolve. There are questions of equity in both the selection of subjects and the sharing of benefits that may result from the research. Under what circumstances is it fair to ask individuals to participate in research that presents little risk but also little chance of benefit to the research subjects, when others - scientists, commercial interests, health care recipients in more affluent societies - could gain substantial benefit?

Scientists sometimes claim their obligation is solely to pursue knowledge and does not include responsibility for the uses that society makes of their discoveries. This argument is overblown. It is questionable in a field such as physics and has no place in the life sciences that depend on the participation of human subjects. Scientists incur obligations when they rely on others to contribute to their enterprise, on the promise of benefitting society. Beyond informed consent and protection from harm, researchers have an ethical responsibility to give their subjects something, not necessarily of material value, in exchange for participating in the research. That "something" may be an attempt to benefit the research subjects or their families. If there is little possibility of such immediate benefit, some benefit from the subjects' participation should flow to their society.

A wide range of benefits to society can be balanced against related costs to individuals. At one extreme, a soldier may lose his life to protect his country. At the opposite extreme, the donation of a biological sample to assist the search for scientific knowledge involves relatively insignificant costs and only speculative benefits. Because the search for knowledge has historically promised little financial reward, the small cost of participating in research has generally been balanced by the potential gain to science. Issues of fairness rarely arose when the potential benefits from research consist only of increased knowledge. Nowadays, however, substantial profit can result from the commercialization of genetic discoveries. Even a small cost of participation by research subjects requires some return in light of the potential gains, to others, from commercialization. These potential gains have focased more attention on the researchers' obligation to human subjects who make the gains possible.

The issues arising in an effort to balance individual and societal interests are illustrated by the debate over the decision of Iceland to permit commercial use of public health records about potentially every inhabitant of the country. Iceland's homogeneous population and extensive genealogical and medical records are a valuable national resource that can facilitate the search for disease genes. Under a recent law, Iceland will grant an exclusive, twelve-year license to a private company, Decode Genetics to link medical and genealogical information from Iceland's national records with genetic information collected by the company. The information from the national records will be provided to the company about all Icelanders except those who request not to be included in the project; the genetic information will be collected only from those who volunteer. Decode Genetics will use the linked information to identify disease genes and has granted Hoffman-La Roche, a pharmaceutical firm, the right to use any genes so identified to develop diagnostic tests and therapies.

In exchange for granting an exclusive licence to Decode Genetics, Iceland will have the use of the company's database to improve the national health care system, and the project will reverse a brain-drain generating some high-tech jobs in Iceland. Also, Hoffman-La Roche has agreed to provide free to Icelanders any tests and drags that result from the project. The monetary beneficiaries of the project will be Decode Genetics, if the company identifies disease genes, and Hoffman-La Roche, if it can turn those discoveries into commercial products.

The project has stirred a debate in Iceland and elsewhere over whether the potential medical and economic benefits to Iceland balance the potential harm to individuals from invasion of their privacy and unauthorized disclosures. The debate revolves around such issues as whether informed consent for inclusion of data in the project should be presumed; whether the confidentiality measures for the database are adequate; whether Decode Genetics should pay for its license; and whether the company should have a monopoly on use of the national records. Opponents of the project argue that the current measures are inadequate to authorize, minimize and compensate the loss of privacy. They have complained, too, that Icelanders may become a "guinea pig population."

The genetic venture in Iceland is unique, but any project involving wide-scale collection of biological samples from a population will raise similar issues. These issues posed by genetic research are more likely to require attention in Turkey than the speculative possibilities of genetic discrimination by employers and insurers. As the controversy surrounding the Icelandic project indicates, researchers who use the genetic resource of a country must respect the individual donors and assure their society will share the benefits of the research. Turkish scientists will find in Iceland's experience a model of policies that researchers should follow or avoid.