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Genetics Between Ethics and Politics: Taking Peoples’ Concerns Seriously

ETİK VE SİYASET ARASINDA GENETİK: İNSANLARIN KAYGILARINI CİDDİYE ALMAK

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Abstract

In recent years, research in medical genetics and biotechnology has made enormous progress and raised tremendous expectations. Yet it may fall victim of its own success. The prospect of curing otherwise incurable diseases and improving the genetic make-up of human beings contrasts sharply with the implications of the genetification of medicine for healthcare and society in general. The paper addresses some of the concerns associated with modern genetics and its applications, particularly as they relate to genetic testing. It argues for a broad-based moral discourse that must involve all relevant stakeholders so as to seek consensus on how genetics should be regulated without jeopardizing its potential benefits.

Key Words: Genetics, genetification of medicine, genetic testing, biotechnology, ethics, moral discourse, transparency, public consultation, regulation

Özet

Son yıllarda, tıbbi genetik ve biyoteknolojideki araştırma muazzam bir gelişme gösterdi ve büyük beklentileri artırdı. Bununla beraber bu gelişme, kendi başarısının kurbanı olabilir. Şifasız hastalıkları tedavi etme kavramı ve insanları genetik olarak düzeltmek, genel olarak sağlık bakımı ve toplum için tıbbın genetifikasyonunun dahil edilmesi ile şiddetle ters düşer. Makale, modern genetik ve uygulamaları ile birlikte olan işlemlerin bazılarından genetik testlemeyle ilgili oldukları için söz eder. Bu makale, nasıl genetiğin potansiyel yararlarını tehlikeye atmaksızın düzenlenmesi gerektiği üzerindeki konsensusu aramak için bütün ilgili kişileri içine alması gereken geniş tabanlı ahlaki bir fikir alışverişini tartışır.

Anahtar Kelimeler: Genetik, tıbbın ğenetifikasyonu, genetik test, biyoteknoloji, etik, ahlak tartışması, şeffaflık, genel danışma, düzenleme

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1. Ambivalent Attitudes

Among the various fields of medical science, human molecular genetics stands out as one of the most advanced. While many of its recent developments have generated great scientific excitement and enormous expectations, they also stirred up deep-seated fears. Science, so it seems, shows nowhere more than in modern genetics its Janus-faced ambiguity by offering the scientific and technological means that can be used to the benefit or to the harm of humankind. The science that, in principle, can cure numerous otherwise incurable illnesses can also cause irreversible damage to our genetic heritage. The ambiguous potential of modern genetics combined with the almost paradoxical situation that modern science (usually) takes place in a public space (research funded with public monies or conducted in the laboratories of public companies) without the public being able to know what goes on, has recently become the focus of concern. Obviously, the complexity and secrecy of modern science contribute significantly to this concern. They have even been utilized to raise suspicions about the overall direction in which genetics is headed. Some of those concerns can be summarized as follows: the reduction of character and individuality to genetic endowment (genetic determinism); the use of genetics in the service of social adaptation and population control (social engineering); the invasion of privacy and the

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(mandatory) transfer of confidential genetic data to insurers and employers; the corruptibility of (medical) sciences through politics and big business hurting particularly the poor and vulnerable members of society; the loss of biological diversity through genetically modified organisms and artificially reproduced (cloned) animals (and in the future perhaps human beings); eugenics and the production of designer babies; the destruction and artificial reconstruction of nature in the image of a synthetic society.

An even more comprehensive list of thirteen clusters of issues has been compiled by ELSI, the spin-off of the Human Genome Project addressing its "ethical, legal and social implications." It identified the following major concerns the Project has raised: Fairness in the use of genetic information; privacy and confidentiality; psychological impact and stigmatization; genetic testing; reproductive issues including informed consent for procedures; use of genetic information in decision making and reproductive right; gene therapy; genetic enhancement; fairness in the use of genetic technologies; clinical issues including education of health service providers, patients, and the general public; quality-control measures in testing procedures; commercialization; and lastly, conceptual and philosophical implications regarding human responsibility and free will as well as concepts of health and disease. In highlighting these concerns and setting aside funds for the thorough analysis of their implications for individuals and society, the unease about modern science in general and biotechnology and genetics in particular seems confirmed.

The single most important question, however, concerns the goal(s) and ultimate purpose(s) of modern science, and this question cannot be answered by science alone. It calls, above all, on ethics to guide individual reflection and political decision making alike. Thus the question is addressed not merely to the scientist but to all of us.

2. Ethical Implications of the Genetification of Medicine

Its has been argued that the increased use of molecular genetics as the sole model of explaining and understanding disease, defining therapeutic practice and determining health policies represents not simply a new phase in medicine but a profound paradigm shift. Genetic models of explanation are becoming more and more powerful and gain significant influence "in medical disciplines and practices that were previously unrelated to genetics." In Lene Koch's view, medicine is being transformed from a form of art, the art of healing, to an exact laboratory science. Such "genetification of medicine", which affects the concept of disease as well as the traditional doctor-patient relationship, is the logical conclusion of a development that began with the discovery of the role of bacteria and viruses in human biology and seems to culminate in a comprehensive theory of human health and disease in terms of genes and their interactions.[1]

Koch has highlighted a clearly discernible trend in the development of modern medicine, which may indeed justifiably be called a new medical paradigm, since it reaches far beyond the boundaries defined by virology and bacteriology. The difference to these earlier models is signified by discoveries that suggest that it is not so much viruses and bacteria themselves which cause disease, but the specific genetic conditions that 'permit' them to do so. That is to say, the genetification of medicine is based on the assumption that the ultimate source of health and of illness is largely identical with the patient's genetic make-up. Thus the influence alien (environmental, social, etc.) factors may have on individual health can be explained as a direct function of a patient's genetic constitution.

While the new paradigm thus marks a decisive step beyond the traditional concept of medicine, its implications are less than clear. In spite of the lack of conclusive evidence, the tendency gains momentum to see in the genetification of medicine the final vindication of medical essentialism, which is based on the hope of an objective, scientific explanation of disease. On this view, molecular biology and genetics provide the definitive parameters for such explanations without recourse to scientifically ambiguous factors such as individual beliefs, personal life styles, social upbringing and related cultural and environmental conditions.

Although most geneticists seem reluctant to endorse such far-reaching conclusions, they are favored all the more by politicians, health administrators, and social engineers who envisage dramatically reduced public spending on health. The fact that research in medical genetics is financed both by the public and private sectors with large biotech companies investing huge sums of venture capital, is a clear indicator of the confidence in the viability and the general acceptance of the new model. It is also a sufficient reason for an in-depth analysis of the moral and social implications the genetification of medicine is likely to have. Whether the optimistic expectations of biotechnology industries and health care agencies are economically justified or not will be of interest only to their shareholders; the implications of the paradigm shift in medicine and its genetification will affect us all, and irreversibly so.

The recent debate in Britain about some of the more visible effects of the genetification of medicine is a case in point. On 11 March 2000, the UK Advisory Committee on Genetic Testing (ACGT) recommended to expand the "range of genetic tests" so as to screen a large proportion of pregnant women, if not all of them, with the aim "of identifying those at higher risk." Those with a family history of illness as well as ethnic groups more susceptible to particular disorders are expected to be tested automatically. Though insurers would not have the power to force people to take genetic tests, they will be able to ask those with a family history of a disease to be tested. According to press reports, insurers believe that in the very near future genetic tests will be widespread and cover a large variety of inherited illnesses.

The suspicion that the British Government has embarked on the road towards an aggressive policy of genetic testing has gained momentum by the initiative of the Human Fertilization and Embryology Authority (HFEA) to seek the public's views on the testing of late onset-diseases such as inherited breast, ovarian, or colon cancer. While embryonic genetic testing for faulty genes that cause such diseases as Cystic Fibrosis and Huntington's is already available at ten fertility clinics in the UK, the public consultation involves preimplantation genetic diagnosis (PGD) that would be used to screen out embryos with conditions that are not "fully penetrant" so that not all children with the defective genes will eventually get sick. As Angela McNab (HFEA's chief executive) has pointed out in her statement of 11 August 2005: "What we are asking people is whether it is appropriate to use embryo screening technology to stop children being born with faulty genes when there is a chance they may never go on to suffer the cancer."

The far-reaching implications of this approach have been promptly highlighted in a response to the HFEA by Calum MacKellar, research director of the Scottish Council on Bioethics (SCB), who sees such tests on "a slippery slope to full-blown eugenics in that what we will probably end up doing is selecting out all defective embryos and having a perfect genetic society" (The Scotsman, 12 August 2005).

In view of the expanding range of genetic tests and their grave consequences for individuals, insurers in Britain have agreed to the government's proposal of a moratorium when the social and health (including health care) implications of such tests will be evaluated. It is, however, inconceivable that insurers and employers would forever resist the temptation to use such tests in their risk calculations and in establishing insurance premiums with the tacit implication that some people will be denied health insurance or employment altogether. The fact that more and more private companies sell genetic tests suggests not only that there is a potentially large and lucrative market for them but also that eugenics is making its comeback. In the absence of effective therapies for genetic defects and abnormalities, the tests can only be used for the selection of healthy embryos and the destruction of "faulty" ones. It may therefore not come as a surprise that doubts have been raised about the integrity of the motives behind governmental screening and testing policies. Some even see mainly economic reasons as the driving forces behind such policies, which use the argument of scientific progress as a smokescreen. As one critic put it: Governments "would rather eliminate unplanned and disabled children than foot the bill for them later on".[2] While this may be an unfair comment, it brings into focus the old yet unanswered question of how we are going to draw the line that separates disease from health and disability from normal functioning, and how far into the future we should extend such definitions of disease and health. In a certain respect, "normal" functioning is as elusive as uniformity in our genetic make-up, which accounts, after all to a considerable extent, for our individuality and the diversity of human appearance and behavior. Yet, as the "perfect" society is anyway an illusion to which not even the die-hard genetic screener would subscribe, the major question genetics raises addresses our personal and social attitudes towards the disabled who will always be with us. How will they fare in a society where disability is likely to become a social stigma rather than a cause for compassion? There is a haunting fear that sooner or later resources will be shifted away from the care for those who for whatever reasons are born with disability to the genetic prevention of disability and, ultimately, to eugenics.

It is, of course, undisputed that governments have a responsibility to promote public health and to prevent disease. It is less clear how to strike the right balance between the justified interests of society and those of the individual. While the screening policies have been decried as government-sponsored policy of the survival of the fittest and an "affront to the dignity of all disabled people," the prospect of people being blacklisted by insurers on the basis of probabilistic risk assessment raises the specter of a genetic underclass of stigmatized people (Sunday Times, 26 March 2000).

Obviously, the ethical challenge of the genetification of medicine appears even more dramatic when the model is extended beyond the parameters of medicine and utilized in the larger social and political contexts of public health and population policies.[3] The increasing genetification of social behavior and of society as a whole is clearly reflected in the escalating search for explanations of individual behavior and social interaction exclusively through genetic factors and dispositions. Yet the hunt for certain defective genes is not simply a matter of scientific interest and unbiased concern for objective knowledge. To a significant degree, it is guided by social and cultural sensitivities, judgments, and prejudices that utilize science for their own purposes and in the service of particular social visions, political programs, or world-views. The excitement over the discoveries of the presumed genetic basis of alcoholism, homosexuality, or aggressive behavior may illustrate this precarious bond that links hard science to cultural traditions and malleable social prejudices. Once again, the prospect of modern science and the ambiguity of its successes confront us with the task to define our own destiny both individually and as a species. This may sound overly dramatic. Yet, if Edward O. Wilson's expectations of genetics and genetic intervention are not completely groundless, genetics is bound to lead humanity beyond the natural lottery and enable us to bring evolution under our own control. In Wilson's view, the advent of genetic medicine and biotechnology marks a new evolutionary period: for the first time it will be possible for humans to "gain conscious control over their heredity" and to suppress "stabilizing selection". Although we are currently only at the beginning of this period, which may result "in a substantial change in human heredity at the population level," on all accounts this period will be pretty short and only of ephemeral significance. It will swiftly take us to the age of "volitional evolution"[4] when, for the first time in human history, we alone will be in charge of our destiny.

While it is difficult to resist the fascination such grandiose perspective of scientifically empowered human self-determination has instilled, at present we seem further away from its realization than Wilson may have thought. The recent discovery that even stem cell lines are, against all odds, not exempt from aging,[5] will at least temporarily dampen high-flying scientific expectations. It may even serve as a wake-up call from exaggerated scientific dreams and as an invitation to ethical reflection. The ambiguity of the scientific empowerment of frail human beings to take the development of humankind into their own hands has faced us with questions that point far beyond science and straight at the core of humanity. In any case, the price for the vindication of freedom from the fetters of nature will be the burden to determine our future without "lodestar" in whose (metaphysical or religious) light we could set course.

3. In Need of a Public Moral Discourse

The time has come when some crucial choices are due that will determine what use we wish to make of our own inventions and scientific discoveries and thus what kind of human beings we want to be. This discussion, however, must be truly open to all interested parties and neither be exclusively conducted in the closed circles of ethics committees nor by so-called ethical experts. Conflicting views on the moral implications of new technologies seem to favor the ethical expert as arbiter in drawn-out and contentious disputes.[6] Apparently, the idea is that, as problems concerning modern science and technology can properly be addressed only by the specialists, the complex moral issues of today equally require the sophisticated tools of certified ethicists who alone are deemed capable of arriving at sound decisions. Their professional expertise is also taken to give them privileged access to moral knowledge the general public is unable to gain for themselves. The large role of ethics committees and governmental advisory bodies are cases in point.

One of the reasons for the apparent plausibility to delegate the necessary decisions to ethics experts and ethics committees or, in the worst case, to politicians, is the degree of complexity and abstractness characteristic of modern science, which obstructs most attempts at the popularization of its achievements as well as the informed debate about their societal implications. The professionalization of ethics is a response to the unprecedented ethical challenges of an ever faster transformation of scientific knowledge into technological applications which have the potential to penetrate deep into traditional life-styles and to irreversibly alter all forms of socialization. The increasing complexity of modern science and technology, which eludes common comprehension and follows nothing but its logic of scientific domination, causes confusion and a sense of helplessness in the face of what appears the inescapable but all-powerful transformation of life. This seems to call for the specialist whose scientific expertise and "superior ability in philosophy" promise ethical orientation that could bring science back under human control and conscientiously direct it towards agreed goals of socio-cultural development. Anybody considering questions about the beginning of human life, its dignity and its worth, or the moral status of the human embryo and the use of embryonic stem cells for research would be expected to have some reliable basic knowledge about genetics and reproductive technology as well as about relevant discoveries in the neuro-sciences. Since it is unrealistic to believe that such knowledge could be found in the general public or that the application of the results of basic scientific research could slow down until the public is ready for their assessment, those who know best are obviously the scientists themselves. And unless we feel comfortable to entrust them with the moral evaluation of their own achievements, the conclusion would be to call for people who are specialists both in the relevant areas of science and ethics.

It is, however, plain to me that such an approach would not simply deepen the gulf that now separates science enthusiasts from science skeptics, but rely on dubious assumptions about the nature of morality and its role in human life. Mary Warnock has challenged these assumptions already some twenty years ago. In her view, moral deliberations about the goals of science and its use in healthcare and medicine must not take place in isolation from the general public and their moral feelings. Particularly in areas of life and death, "no-one is prepared to defer to judgments made on the basis of a superior ability in philosophy. For these are areas which are central to morality, and everyone has a right to judge for himself", and, she concludes, "that is why there cannot be moral experts".[7]

While the ethics expert can be expected to correctly analyze ethical issues in the light of the relevant ethical theories, such professional expertise is neither a guarantee for proper moral advice for action nor is it independent of the ethos of a particular society. For both the goals of social action and their moral foundation in the cultural history of society are not in the domain of any individual. Instead, they seem to be accessible only through a process of interpersonal communication and moral cooperation in which every human being has a voice that must be heard, at least in principle. While the individual person is the ultimate judge about the morality of his or her intentions, the morality of the consequences of individual actions for society as a whole can only be clarified in a communicative process and moral discourse that transcends the individual towards a broad and socially endorsed moral consensus.

According to a British survey, openness and honesty are most important to maintain trust in regulatory systems of fertility treatment and embryo research, followed by knowing that there is a system which will stop particular actions if there are concerns. While politicians, religious leaders and the media are trusted by relatively few people to be involved in the regulation of fertility treatment or embryo research, there is a strong feeling that the framework of rules and regulations should be developed by doctors and parliament working together to develop a consensus. Based on the survey, HFEA has issued the following recommendations that merit close reading:

"A consensus between public, doctors and scientists is essential to maintain public confidence which allows treatment and research to continue and progress. Public opinion is finely balanced and fragile and requires continued openness, honesty and a consensual approach. The public want authoritative and trusted information and will trust an independent regulator to provide it. It is important for regulators to assess and evaluate public opinion on an ongoing basis to maintain confidence in the face of scientific developments. Patients can feel differently about these issues and are influential on others. Therefore, it is important to track the views of patients separately".[8]

The fact that ethical advisory and policy committees have been set up almost everywhere in the world illustrates how complex the issues in genetics and embryo research have become. While it is certainly true that moral decisions cannot be delegated to experts but must firmly remain with all those affected by them, it is equally true that decisions in ethics must be based on reliable information of all the relevant factors concerned. There may be no direct path from "facts" to "values" (though - as Bernard Williams and others have pointed out - the meaning of this question is less clear than commonly assumed) but this implies neither that ethics debates take place only at the meta-level of general moral principles nor that the moral feelings of the public would be the most reliable guide for ethical decision-making in the public domain. This suggests that both the superior ability in philosophy and the scientific expertise in basic bio-research as well as in bio-technology must be utilized to facilitate a broadly based communicative process of mediation between the research community and the general public. Though it is neither feasible nor desirable to entrust scientists with the ethical evaluation of their own research, their active participation in the communicative process of moral decision making, particularly at the social level, is most needed. Scientists (and medical doctors) would seem to have a heightened responsibility for the accurate transfer of specialized information and its sensible interpretation. Since not all of them are equally capable to play a meaningful role in the mediation of scientific knowledge to the public, new forms of communicative interaction need to be developed. One way to involve the scientific community more directly and responsibly in this process could be accomplished through new forms of scientific representation at the professional level that would also lead to greater transparency in the management of scientific knowledge. For this purpose, it has been suggested that, at national levels, the scientific community should elect among themselves suitable representatives who during a clearly specified term would serve as their authentic spokespersons and the objective interpreters of the results of scientific research.[9]

Obviously, much procedural attention would have to be placed on the inclusion of specific safeguards that would prevent these representatives from turning into nothing more than cleverly disguised lobbyists for specific (scientific, economic, political, ideological, etc.) interests. While the participation of public research foundations and similar organizations in the electoral process could provide structural support as well as a high degree of authenticity, the scientific reputation and public accountability of the elected representatives would seem to reduce to reasonably acceptable levels the risks of abuse inherent in any form of public representation.

Though such common-sense approach within the framework of the modern consensus-driven democracy leaves yet unanswered some of the wide-ranging questions about the relationship between expert cultures, common morality, and legal and political decision making, it would at least facilitate a public discourse that would give anyone interested a reasonable chance of participation. Hopefully, it would also reduce the extent of distrust and disinformation the complexity of modern science in general and in the bio-sciences in particular usually generate in large sectors of society. Public moral discourse requires broad inclusion of views, procedural transparency, openness, and fairness.

The recent European Bioethics Convention, which has been criticized for failing to meet these requirements, may serve as an illustration of both the need for more transparency and participation in the public debate about morally sensitive research and the difficulties a truly public moral discourse still has to overcome.

The drafting process has been charged with professional exclusivity, undue influence of individual governments, and a lack of transparency. While this may have favored a broader agreement on many contentious issues than would have been otherwise possible, it did in fact neither lead to a consensus, however diplomatically diluted, nor to an unbiased evaluation of the moral implications of medical science. The uneasy compromise reached on various issues has been put in jeopardy or partially been revoked in the Explanatory Report attached to the main document. It has been noted that neither the Convention nor the Explanatory Report did "develop a consistent methodology or philosophical argument that one could systematically discuss".[10] The same critic has argued that the Convention is also based on a "techno-scientophobic" prejudice about genetics and a general suspicion about modern science and the desire to know: "The will to know and the desire to increase knowledge are suspect and the link between the progresses of science and technology are described as most questionable".[10]

Though this is not the place for a detailed analysis of the Convention, it seems clear that if these allegations can be substantiated, they would considerably weaken the argumentative force it may otherwise have. They may also cast doubt on the document's ability to foster moral consensus and to provide a lasting and comprehensive legal and moral framework for the application of modern science in healthcare and medicine. The Convention is, after all, not simply of declaratory intent but the blueprint for legislation in the member states of the European Union and beyond.

In conclusion, contemporary research in genetics and molecular biology is an exciting achievement that deserves our applause and support. Since it simultaneously raises some major questions about ourselves, the society we would like to live in and the prospects for a moral consensus in a global perspective, it prompts us to reflect more deeply than usual on the fundamental values and the moral vision that have guided our lives in the past. It challenges us to clearly identify and, if necessary, recover the basic frame of reference within which our idea of human goodness and morality has taken shape. The question will be how we are going to define the parameters of what Avishai Margalit has called the decent society where no one will be humiliated and denied the fundamental respect he or she deserves as a human person.[11] The answer to this question is likely to determine whether, and if so, where we need to draw the line for our insatiable curiosity and the instinct of discovery, on what moral basis, and by what mandate.

REFERENCES

1. Koch, Lene. "Predictive Genetic Medicine-A New Concept of Disease." In: Elisabeth Hildt and Sigrid Graumann, eds. Genetics in Human Reproduction. Ashgate: Aldershot, 1999. p.185-95.
2. McCartney, Jenny. "Memento Mori." Sunday Telegraph, 12 March 2000.
3. Kaminsky, Carmen. "Genomanalyse: Absichten und mögliche Konsequenzen in der Perspektive angewandter Ethik. In: Eve-Marie Engels, eds. Biologie und Ethik. Reclam: Stuttgart, 1999. p.194-233.
4. Wilson, Edward O. Consilience: The Unity of Knowledge. In: Alfred A, ed. New York: Knopf; 1998.
5. Maitral, Anirban et al. "Genomic Alterations in Cultured Human Embryonic Stem Cells." Nature Genetics (published online 4 September 2005).
6. Singer, Peter and Deane Wells. The Reproduction Revolution: New Ways of Making Babies. Oxford: Oxford University Press; 1984.
7. Warnock, Mary. A Question of Life. The Warnock Report on Human Fertilisation & Embryology. Blackwell: Oxford, 1985.
8. "Public Attitudes to Fertility Treatment, Embryo Research and the Regulation of this Work. Preliminary Findings from the UK. HFEA Policy Briefing Presented to members of the European Assisted Conception Consortium," July 2005 (http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/Screeningforlowerpenetrancecondition.
9. Singer, Wolf. "Wir brauchen kritischen Wissenschaftsjournalismus." Frankfurter Allgemeine Zeitung, 9 July 2001. p. 47.
10. Hottois, Gilbert. "A Philosophical and Critical Analysis of the European Convention of Bioethics". J Med Philosophy 2000;25:133-46.
11. Margalit, Avishai. The Decent Society. Cambridge University Press: Cambridge, 1996.