

Genetic Advances Require Comprehensive Bioethical Debate

Henk A.M.J. ten Have

Department of Ethics, Philosophy and History of Medicine, University Medical Center Nijmegen, Nijmegen, The Netherlands

In the popular media and scientific literature, the idea of medical utopia seems to have been revived. Medical science and technology are expected to provide solutions for all kinds of daily problems in human existence. The utopian context and optimistic atmosphere are influencing deeply the bio-ethical debate concerning bio-molecular technologies. They *a priori* direct this debate towards individual perspectives, emphasizing the benefits among which an autonomous person can make his or her choice, and towards practical applications the potential beneficial effects of which are almost there. It is argued that the concept of "geneticization" is useful for the analysis of the interrelations between genetics, medicine, society, and culture. This concept focuses on conceptual issues – the use of genetic vocabulary to define problems; institutional issues – the emergence of bio-ethics experts; cultural issues – the transformation of individual and social attitudes under the influence of genetic knowledge and technology; and philosophical issues – changing views of human identity, interpersonal relationships, and individual responsibility.

Key words: *bioethics; biotechnology; culture; genetics; personal autonomy; philosophy; utopias*

French philosopher Luc Ferry refers to a story of a young mother in the times of Buddha (1). Her baby has succumbed to a lethal disease. Exhausted by grief, the mother wanders through the streets and appeals to other people to help her. Finally, she meets Buddha; she puts down the corpse of her son at his feet, and begs him to revive her child. Buddha whispers that there is only one remedy against her misery: she must go into town and return to give him a mustard-seed from a family home in which nobody has ever died. The outcome of Buddha's request is clear, according to Ferry. Obtaining the seed is not a problem, but every family has members deceased.

This type of story about death, dying, and grief is paramount in all major religions and spiritual traditions. They indicate that death and disease are intrinsic components of human life. No matter how much we strive to live healthy, disease will finally overcome. Philosophical schools, such as Stoicism, have underlined the transient and finite nature of the world. Philosophy is an exercise in how to die. Wisdom is the acceptance of finiteness. Human existence is characterized by the tension between love and death, or friendship and living together on the one hand, and separation, loss, and extinction on the other. Those who ignore this fundamental tension are really exposing themselves to existential suffering.

However, in the new millennium, this old wisdom seems hopelessly antiquated. Modern human beings are destined to progress, to design the future,

and to overcome any limitations. They are finally recognized, at least in moral theory, as autonomous individuals who themselves attribute meaning to their existence and choose the projects they value. Science and technology are the most important instruments to make life more valuable; they provide the means to individuals to liberate themselves from the tragic dimensions of nature, particularly the absurdities of disease, aging, and death. In this perspective, it is obvious that medicine has emerged as the most influential and socially relevant science. The expectation is that medical science and technology will provide solutions for all kinds of daily problems in human existence.

Medical Utopia

The development of modern medicine has been inspired by the ideal that human ailments could be conquered by the progress of science. The philosopher René Descartes (1596-1650) argued that medicine can progress if it is based on contemporary science, especially physics and chemistry (2). All sciences can be represented in the image of a tree: the roots are philosophy, the trunk the natural sciences, the branches all other sciences. Ultimately, the tree will bear fruit, particularly in the domain of medicine. Although nothing in medicine at that time suggested this potential, Descartes hypothesized that human ailments could finally be eradicated; they are not neces-

sary components of human existence as long as we attempt to improve medicine.

The belief in medical progress developed beyond Descartes' hypothetical approach during the Enlightenment. Self-confident assertions and predictions took the place of uncertain guesses and hypotheses. For example, Marquis de Condorcet (1743-1794), one of the ideologues of the French Revolution, expounded a far-reaching optimism. The means to improve human beings will not only become available through the progress of science, but it will also be obvious that there is a wide range of possibilities for improvement as long as human beings are concerned. Condorcet pointed out that "...the perfectibility of the human being is in reality indefinite" (3). Contrary to earlier utopian thinking, the new sciences will not merely help us overcome and eradicate the age-old ailments and suffering of human beings, but they will rather enable the human person to perfect herself or himself. Ultimately, medicine will be transformed from curing and preventing illness into promoting well-being and enhancing human existence.

Utopia Realized?

What Descartes and Condorcet regarded as an ideal that could be realized if we focus on the further development of science was for earlier generations nothing more than a dream, a phantasmagoric longing for Paradise lost. This dream has been visualized over and over again in art and literature. A famous example is the painting *Der Jungbrunnen* of the 16th century artist Lucas Cranach. It shows an ancient spa resort; from the left side, old, diseased, and crippled persons step into the thermal waters; being fully immersed, they leave the bath at the other side, completely rejuvenated, healed, vigorous, and able-bodied.

In our own times, we have a different situation. What started as a dream became a realistic ideal, and has now grown into the situation that many people seem to believe that utopia has almost been realized. The general idea is that we are at the brink of a crucial transformation of our potentials. We are witnessing the emergence of a new medicine, which is no longer focused on the treatment of the consequences of diseases, but on the submicroscopic causes of diseases. These causes are considered to be subject to elimination through therapeutic interventions that interrupt the processes leading from a gene to the symptoms. The new medicine will furthermore develop preventive strategies to identify the predisposition to develop diseases, as well as the tests necessary to detect this predisposition in an early stage. The changes in medical science and practice under way at the moment prognosticate the enormous potential of molecular interventions, which may soon be attainable. The ideals that were imagined by Descartes and Condorcet appear to be approaching the stage of implementation.

The current *Zeitgeist* is demonstrated not only in the popular media but also in scholarly publications. The thesis of a recent book of a well-known health economist and health policy expert is that medical utopia is nearly realized (4). The emergence of a to-

tally new range of possibilities to enhance and perfect human existence fascinates the public imagination. Recent scientific advances, such as egg donation, post-menopausal motherhood, embryos by mail order, and ovarian transplants extend reproductive choices. At the same time, the suggestion is that we will be able to "design" babies – free of defects, healthy, and of preferred sex, color, and qualities (5).

Bio-technologies will also alter the human body. Body materials are engineered and produced in laboratories; body parts are stored in special banks; and cells, tissues, and organs are exchanged (6). Body materials are sources of information (e.g., for forensic purposes) and raw materials for commercial products. The human body has become the final battleground for the market ideology. Our bodies are considered as exploitable resources, commodified and transformed into market products (7).

The utopian expectations are culminating in today's acclamations of stem cell technology. We even have the mechanistic vocabulary: "replacing failing parts", "neo-organs", "off-the-shelf organs", "prefabricated spare parts", suggesting that all components of the body can be repaired in the body shop. The ancient ideal that we can finally be free from the limitations of the human body because diseases, at least in principle, can be eradicated, and age almost infinitely extended, is not far from being substantiated.

Focus of Moral Debate

Utopian expectations as well as overly optimistic views of bio-technology have consequences for the moral debates regarding appropriate use of these technologies. In particular, they pre-arrange the debate and provide a set of "advance directives" for the issues that should be at stake.

Furthermore, moral debate concerning genetic technologies is usually focused on individual perspectives and practical applications, and new discoveries and research findings in the bio-molecular life sciences are rapidly presented and discussed in the media. These discussions tend to highlight the impact of genetics on individuals as the principle of respect for the autonomy of individuals is often the starting-point for considering the implications of the use of genetic interventions. Emphasis is on the proper management of information by individual citizens, informed consent, privacy regulations, the right to know, and the right not to know. The moral debate is also affected by the public fascination with new data, devices, and discoveries and a rush to practical applications. Often, benefits for medical advancement are pointed out very prematurely. The purpose of the moral debate should be to develop guidelines and standards for the appropriate use of gene technology, following various moral principles, rights, and rules that have been developed to delineate what is regarded as appropriate use.

Limitations of Debate

While utopian expectations create pressure to apply knowledge prematurely, comprehensive ethi-

cal assessment should precede application. This requires prior identification of the goals that we want to accomplish by using the knowledge, careful balancing of the benefits and harms generated through the application of that knowledge, and delineation of the norms and values that should be respected. However, efforts to delineate guidelines, codes, standards, or rules for the application of new knowledge and technology before evaluating the entire conceptual and social framework generating new genetic technologies, are also inappropriate.

It is also inappropriate to focus entirely on individual autonomy. It is often argued that genetic information is special and that it, therefore, requires special ethical treatment. Genetic knowledge is not private information, but necessarily implies relatives. Genetic information is also potentially valuable to third parties, such as insurance companies, employers, and prosecutors. Genetic technology can affect future generations. For these reasons, the focus on autonomy is too limited. The challenge of the current development of genetics is not to individuals primarily, but rather to societies.

Social Dimension of Genetics

Ethical analysis should address the social and cultural context within which genetic knowledge is promulgated, as well as the social processes involved in the dissemination of genetic technologies. The ever growing impact of genetic technologies on society as a whole, and their diversified cultural manifestations should lead, for example, to a critical attitude towards moral statements that individual persons are free to choose among available genetic options exclusively on their desires and needs, and that the development of unwanted scenarios involving others is unlikely. Other pressures are directly influencing the use of genetic knowledge, for example, through the application of genetic testing in prenatal care and various insurance arrangements, as well as indirectly through new imagery and concepts of health, disease, disorder, and abnormality (8). Analysis of film, television, news reports, comic books, ads, and cartoons shows that the gene is a very powerful image in popular culture. It is considered not only as the unit of heredity, but as a cultural icon, an entity crucial for understanding human identity, everyday behavior, interpersonal relations, and social problems. The growing impact of genetic imagery in popular culture has been related to "genetic essentialism," the belief that human beings in all their complexity are products of a molecular blueprint (9). Moreover, the concept that genetics can be used to create postmodern human beings also has repercussions for healthcare and medicine, as well as science in general. Molecular biochemistry now has stronger claims to be the fundamental science in medicine and the life sciences than ever before. The general conviction that future genetic possibilities will drastically change medical diagnosis, treatment, and prevention is increasingly being discussed, but the needs for moral discourse are often not clarified. To identify and analyze the various cultural processes related to the bio-molecular life sciences, the concept

of "geneticization" has been introduced in the scholarly debate.

Geneticization

The concept of "geneticization" aims to describe the interlocking and imperceptible mechanisms of interaction between medicine, genetics, society, and culture (10). Western culture is, supposedly, deeply involved in a process of geneticization. This process implies a redefinition of individuals in terms of DNA codes, a new language to describe and interpret human life and behavior in a genomic vocabulary of codes, blueprints, traits, dispositions, genetic mapping, and a gene-technological approach to disease, health, and body. We can define geneticization as the socio-cultural process of interpreting and explaining human beings with the terminology and concepts of genetics, so that not only health and disease but also all human behavior and social interactions are viewed through the prism of biomolecular technology (11,12).

This new concept tries to make explicit what is often not well articulated in our culture's fascination with genetics. Genetic technology is not merely regarded as a new technology that is available for responsible use by autonomous consumers, but rather as a potential transformation of human understanding and existence. Genetics is regarded as more than a science, as a way of thinking, an ideology: "Whatever the question is, genetics is the answer" (13). Genetic thinking is considered a way of understanding the world, genetic practice is a way of imagining the future.

The concept of geneticization may indeed produce a change of focus; it can direct scholarly attention to dimensions of genetic technology, which are usually neglected in bio-ethical analyses.

Medicalization

The medicalization debate that occurred in the 1970s provides an analogy with the concept of geneticization. Lessons from that debate can be used to develop an analysis of the socio-cultural impact of gene technology. Medicalization, as well as geneticization, is in fact an example of more general, encompassing processes. *Prima facie*, there is much similarity with the philosophy of normalization advanced by Michel Foucault: since the early 19th century, medicine creates social order by its polarized distinction between "illness" and "health" (14). The theory of medicine (classification of diseases), the human body, and society as a whole became closely interconnected. Bio-politics transforms human beings into subjects. There is no escape from medical power; even the requests of patients can be regarded as an extension of medical power. This is the Janus-face of medicalization: at the same time as it provides certain benefits (patients have effective treatments), it also subjects them to certain forms of discipline (treatment regimes and monitoring).

However, medicine is not simply "medicalizing." Instead of using domination and control, the

field of medical power has been reformulated (15). The locus of medical power is no longer the individual physician but large, pervasive structures encompassing physicians and patients alike. Medical power is no longer exclusionary either, but has become inclusive; challenges from alternative healthcare, holism, bio-ethics, and hospice movement are rapidly incorporated into "orthodox" medical practice. The new field of medical power, therefore, is not so dependent on domination and control as it is on monitoring and surveillance. Technologies of monitoring and surveillance incite discourse; they make the intimacies of the patient visible, they leave visible records. Everything must be noted, recorded, and subjected to analysis.

Analysis of Geneticization

Medicalization is associated with several consequences: it is a mechanism of social control through the expansion of professional power over wider spheres of life; it locates the source of trouble in the individual body; it implies a particular allocation of responsibility and blame; and it produces dependency on professional and technological intervention (16,17). The concept of geneticization can be analyzed at various levels by drawing an analogy with processes of medicalization. Namely, it can be analyzed (a) conceptually, when a genetic terminology is used to define problems; (b) institutionally, when specific expertise is required to deal with problems; (c) culturally, when genetic knowledge and technology lead to changing individual and social attitudes towards reproduction, health care, prevention and control of disease; and (d) philosophically, when genetic imagery produces particular views on human identity, interpersonal relationships and individual responsibility. In contradistinction to medicalization, the concept of geneticization seems to be broader because it also refers to developments and differences in the interaction between genetics and medicine. There is, for example, no expansion of concepts of health and disease into everyday life, but a fundamental transformation of these concepts themselves. In medicine, there is also a tendency to use a genetic model of disease explanation, as well as a growing influence of genetic technologies in medical practice (8).

Geneticization and Ethics

Using the concept of geneticization also requires a critical analysis of theoretical developments following the introduction of the medicalization thesis. Particularly the perspective that patients are not passive "docile bodies" under the control of medical power, but articulate consumers and autonomous decision-makers needs to be taken seriously, because the moral requirements of non-directiveness and respect for individual autonomy are strongly emphasized in present-day clinical genetics. However, this emphasis on autonomy tends to forget that social arrangements frequently pre-determine the range of choices available to individuals in a particular society. An example of processes of geneticization is the case of screening and counseling programs for beta-thalassemia in Cy-

prus (18). In this society, individuals can only marry if they have a certificate showing their participation in genetic screening. Although the priest is not allowed to inquire about the outcome of the test, the question is what implications this knowledge has for the behavior of tested young adults themselves.

The notion of geneticization introduces at least four issues in the bio-ethical debate that provide a wider perspective on the moral dimensions involved.

Self-interpretation

Society is involved in a process of geneticization (19). This process involves a redefinition of individuals in terms of DNA codes. Disease, health, and the body are explained in terms of molecular biology. Nelkin and Lindee (9), examining popular sources such as television, radio talk shows, comic books, and science fiction, showed how popular images conveyed a picture of the gene as powerful, deterministic, and central to an understanding of both everyday behavior and the "secret" of life. It seems that for human beings the cultural meaning of DNA nowadays is remarkably similar to that of the immortal soul of Christian theology. The current emphasis on individual autonomy is therefore paradoxical: it underlines individual freedom, but also considers genetic determinants as the essence of human beings. At the same time, the focus on the individual genetic make-up, of course, is an oversimplification, which should be redressed in bio-ethical discourse.

Manipulative Action

The bio-information and cartography metaphors, often used in the context of the genome project, are in fact re-workings of a mechanical metaphor, which has been frequently used in the past in medical discourses on the body. These linguistic (and often visual) representations of the body carry with them the importance of a technological approach: machinery is used to fix machinery. They represent the body as being comprised of a multitude of interchangeable parts (20). Genetic interpretation carries with it the notion of possible intervention. Not only will such knowledge enable people to foretell their individual fates from reading their genes, but it will also enable them to adapt their life plans in accordance with these predictions, and ultimately, to intervene and ameliorate the initial determinations. However, the danger is that simplistic models of the body will dominate the life sciences, interfering with a more sophisticated understanding of the human body as more than a biological organism (21).

Mixed Blessings

Geneticization generates potential benefits and harms at the same time. The growth of genetics promises a potential elimination of diseases. In particular, it can decrease the burden of congenital disorders. Simultaneously, it requires increasing control and discipline to reach these goals; the population has to be educated and instigated to seek testing and counseling. It also expands the range of conditions for which

testing is feasible, so that not merely diseases as such will be the target of testing, but pre-dispositions and susceptibilities as well, thereby creating a new category of "pre-patients" or "potential patients". What is needed here is a redefinition of the concept of disease, focusing neither on the clinical symptoms nor genetic abnormality, but rather on the increased risks of adverse consequences to individuals (22).

Dynamics of Science

It is not generally appreciated that many claims about the potentials and advantages of genetics are either exaggerated or insubstantial. The history of science reporting is not an unbiased road to victories. The public presentation of new findings is often extravagant compared with the real state of the art. However, due to pressures of reputation, prestige, resources, and growing intertwining of academic and commercial interests, the scientific status of many claims is often unclear or flimsy. Gene talk is a powerful tool of persuasion. Ethical debate should at least assume a more critical and skeptical attitude towards these claims. The very success of genetic discoveries has in fact undermined the concept of the all-powerful gene, so that the "secret of life" has become more mysterious and complicated, and simple images of reductionism and determinism less plausible than before (23).

In conclusion, we may say that rapid advances in genetics are likely to have an enormous impact on society and individuals, requiring comprehensive discussion and debate before application. The concept of geneticization discloses particular areas for philosophical scrutiny and redirects and refocuses moral discussion. The concept particularly draws attention to social issues that tend to be neglected or disregarded because of the current domination of the moral principle of respect for individual autonomy. It also allows bio-ethics to criticize the oversimplifications in current approaches to genetics, and to rethink common concepts of "disease", "health", and "body". The concept, therefore, informs bio-ethics that bio-medicine and bio-science should be associated with bio-criticism.

References

- 1 Ferry L. *Man-made God: the meaning of life* [in French]. Paris: Grasset et Fasquelle; 1996.
- 2 Descartes R. *On the method* [in Dutch]. Amsterdam: Boom; 1977.
- 3 Condorcet. *Oeuvres de Condorcet*. O'Connor A, Arago MF, editors. Paris: Firmin-Didot; 1847-1849.
- 4 Schwartz WB. *Life without disease: the pursuit of medical utopia*. Berkeley (CA): University of California Press; 1998.
- 5 Gosden R. *Designing babies: the brave new world of reproductive technology*. New York (NY): WH Freeman and Company; 1999.
- 6 Kimbrell A, Rifkin J. *The human body shop: the engineering and marketing of life*. London: HarperCollins; 1993.
- 7 Andrews L, Nelkin D. *Body bazaar: the market for human tissue in the biotechnology age*. New York (NY): Crown Publishing Group; 2001.
- 8 Hoedemaekers R, ten Have HA. Genetic health and disease. In: Launis V, Pietarinen J, Raikka J, editors. *Genes and morality. New essays*. Amsterdam/Atlanta (GA): Rodopi; 1999. p.121-43.
- 9 Nelkin D, Lindee MS. *The DNA mystique: the gene as a cultural icon*. New York (NY): WH Freeman; 1995.
- 10 Lippman A. Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *Am J Law Med* 1991;17:15-50.
- 11 Lippman A. Prenatal genetic testing and geneticization: mother matters for all. *Fetal Diagn Ther* 1993;8(Suppl 1):175-88.
- 12 ten Have HA. *Genetics and culture: the geneticization thesis*. *Med Health Care Philos* 2001;4:295-304.
- 13 Rothman BK. *Genetic maps and human imaginations: the limits of science in understanding who we are*. New York (NY): WW Norton and Company; 1998.
- 14 Foucault M. *The birth of the clinic: an archaeology of medical perception*. London: Routledge; 1993.
- 15 Arney WR, Bergen BJ. *Medicine and the management of living. Taming the last great beast*. Chicago (IL): Chicago University Press; 1984.
- 16 Illich I. The medicalization of life. *J Med Ethics* 1975;1: 73-7.
- 17 Zola IK. In the name of health and illness: on some socio-political consequences of medical influence. *Soc Sci Med* 1975;9:83-7.
- 18 Hoedemaekers R, ten Have HA. Geneticization: the Cyprus paradigm. *J Med Philos* 1998;23:274-87.
- 19 Lippman A. Led (astray) by genetic maps: the cartography of the human genome and health care. *Soc Sci Med* 1992;35:1469-76.
- 20 Lupton D. *Medicine as culture: illness, disease and the body in Western societies*. London: Sage Publications Ltd; 1994.
- 21 Levin DM, Solomon GF. The discursive formation of the body in the history of medicine. *J Med Philos* 1990;15:515-37.
- 22 Temple LK, McLeod RS, Gallinger S, Wright JG. Essays on science and society. *Defining disease in the genomics era*. *Science* 2001;293:807-8.
- 23 Keller EF. *The century of the gene*. Cambridge (MA): Harvard University Press; 2000.

Received: December 10, 2002

Accepted: August 12, 2003

Correspondence to:

Henk ten Have
Department of Ethics, Philosophy and History of Medicine.
University Medical Center Nijmegen
PO Box 9101
6500 HB Nijmegen, The Netherlands
h.tenhave@umcn.kun.nl