

The genome and public choices: new questions for Anthropology

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Summary - *The advances in genomic research are deeply changing many aspects of biological research. In fact, they have altered the relationships between nature and body, chance and choice, necessity, freedom and possibility. While some basic certainties are now being challenged, the discussion concerning biosciences is becoming an opportunity to rethink the processes of reorganization of scientific research, focusing on the implications for social sciences, law and politics. An excellent exemplification and a case of particular interest to Anthropologists is provided by the issues surrounding the mass genetic screening in Iceland. This transformations require a model of cultural growth, not an uncritical neo-positivism, but an effort to define analytical categories capable of absorbing and interpreting the directions impressed by recent scientific advances on the process of civilization.*

Keywords - *Genetic information, Equity, Ethics, Socialization, Governance*

Introduction

In one of his "American Lessons", the one dedicated to the concept of 'Multiplicity', Italo Calvino asks: "Who are we, who is each one of us if not a combinatorial of experiences, information, readings, imaginings? Every life is an *encyclopaedia*, a library, a catalogue of objects, a sample collection of styles, where everything can be constantly mixed and reordered in all possible ways" (Calvino, 1988). Calvino's argument is a kind of *manifesto* of post-modernity, and is constructed in order to define a philosophy of the literary text viewed as a hybrid of knowledge and culture where the challenge lies in thinking in a conjoint fashion about forms and events that are conventionally opposed. The issue raised by Calvino nevertheless seems to overstep these boundaries and to translate into a metaphor of the scientific revolution that we have been experiencing in the last few years versus which ethic thinking must come to terms with phenomena that occur in border areas where

forms and structures arise and are dissolved (Grmek, 1999). Under pressure from the cultural fracture what have been found wanting are the interpretative categories based on concepts we previously considered immutable, such as life/death, natural/artificial, disease/cure, body/personal identity, production/market, intellectual property/sharing, which are liable to be misleading as regards providing answers to the emerging questions (Buchanan *et al.*, 2000). The birth of bioethics and its astonishing development cannot therefore be separated from this new mingling of scientific breakthroughs, political cultures, and social subjects that demands that a new ethics be formulated that can cope more satisfactorily with the challenges and changes produced. The worst error we could commit would be to enter the new era with the traditional theoretical and ethical baggage, applying to the problems new solutions developed in a different historical phase and without defining new hypotheses in the field of public ethics (Berlinguer, 2000; Singer, 1996). The focus of the present work

will thus be concentrated on a few general and widely controversial themes which will allow us to understand more fully what is really at stake today and the questions for which an answer must be found.

Genetic information: epistemology, ethics and equity

DNA is the molecule that contains the genetic information regarding an individual – the *genotype*; when it is expressed (i.e. when it implements its information), the DNA creates a *phenotype* which consists of that portion of the genetic information that is expressed directly, which becomes apparent (Watson & Crick, 1953). DNA is therefore not an abstract idea, it is not information stored on a diskette, it is a three-dimensional chemical molecule that can be measured, collected and organized. All this shakes ontological personalism to its very foundations as it presents us with a process-based view of the structure of living systems, in which different levels – chemical, physical, temporal and spatial – coexist in an apparently contradictory fashion that is nevertheless functional and necessary to enable the genotype and the phenotype to be expressed, conserved and to evolve. To this must be added another extremely important concept: if we take three organisms and check whether they are genetically the same or different, what we find is that they are substantially almost identical; the internal variability of the organisms is minimal, even though it is a real and measurable phenomenon. These small differences are what justifies evolution and it is precisely these small differences that to a certain extent give a sense to life. In a word, these discoveries tell us there is nothing “magical” in the organization of life and in the production of substances that form the basis thereof, which move, travel, become organized material and, if the organization has sufficient time and energy to attain certain levels, simultaneously become genotype and phenotype (Adami, 2004; Waters, 1994). The series of discoveries that, in recent decades,

have revealed these characteristics of DNA and in particular that of being a physical and transmissible molecule, have allowed the transition from an exclusively descriptive interpretation to a quantitative type of interpretation of living systems (Woese, 2004). For instance, molecular analyses such as the microarrays of gene and protein expression allow us to make a more accurate diagnosis of many pathologies, as well as to adapt therapies to the exact characteristics taken on by the disease in each patient (Zweiger, 2002). At the same time, however, they convert biological information into electronic information. In this way an individual's genotype may be analysed and classified and, as such, may be reduced to a medical device, a database resource. The aim of this huge collection of data is to exploit the characteristics of those communities that, having lived in relative isolation, have acquired a homogeneous genetic “inheritance” that allows of targeted research aimed at identifying the genetic mutations underlying certain diseases. At the same time, however, the development of bioinformatics and the construction of increasingly large and precise databases foreshadow a process of dematerialization that, in actual fact, introduces the risk of everything being transformed into a sophisticated strategy for making human biological materials available to the market and to science which becomes capable of sidestepping the democratic constraint of informed consent via a procedure whereby the body is reduced to mere information (Andrews & Nelkin, 2001).

The Iceland case

This set of issues may be analysed concretely in the case of Iceland where, in December 1998 a law was passed authorizing the creation of a database of genetic information pertaining to the entire population on a voluntary basis and with specific guarantees extended to those agreeing to the collection of their data, which were rendered anonymous on being entered into the database

(Árnason, 2004). Subsequently, in 2000 deCODE Genetics, a private company run by an Icelandic researcher Kari Stefansson was authorized to construct and manage the Icelandic healthcare database upon payment of a yearly subscription. Needing tissue, cell and blood samples for its research, deCODE Genetics initially appealed to volunteers, following the procedure adopted in the 1998 “Medical Database Act” which imposed explicit consent. As it encountered difficulty in making this collection, deCODE then managed to get the regulations changed: the “Biobank Act” of 2000, which allows the use of existing samples on the basis of the assumed consent of the persons concerned, who are entitled solely to exert the right of refusal (Greenhough, 2006). The project entails linking all the hospitals and treatment centers in Iceland into a single network connected to a central computer in which all the data collected by physicians concerning their patients is entered, together with the information previously collected on the deceased population (which is available in a detailed form in recent decades in the public healthcare service), the detailed genealogical trees that have been conserved for some time in the churches scattered over the country and data regarding blood and tissue samples. deCODE purchased the right to use the data contained in the database for a period of twelve years and for the purpose of economic gain. For its part it must shoulder the costs of data collection and construction of the database, pay the Iceland authorities the cost of preparing the licence and annually those of its application, including the functioning of the Ethics Committee and any access of the database by the minister of health (Merz *et al.*, 2004). The Iceland case has shown up several critical and paradigmatic points regarding the issues raised by the use of genetic information, which may be summed up in three fundamental questions:

- a) Is it legitimate to sell the genome of an entire population?
- b) Is it legitimate to facilitate the constitution of monopolies in this sector?

- c) Is it really possible to speak of the right to confidentiality through the anonymity of information in a community where it may prove easy to identify those having given diseases, with the attendant risk of discrimination in the workplace or in the insurance sector?

It is clear that in this case, which is similar to that of Estonia, the Island of Tonga and other small communities scattered throughout the world, there is growing resistance to mass genetic cataloguing, against the transformation of the genome into a commodity, against the total genetic transparency of persons. Moreover, some of the criticism accompanying the project inside and outside Iceland would have been avoided if the data collected had been made available to the entire scientific community, on equal terms and without demanding any economic recompense. However, the aim of the States was instead precisely to make a profit by exploiting a particular, unique, good – namely the genetic inheritance of the populations. And pursuing this aim, also the guarantees planned for the citizens ended up by being pushed into the background (Rodotà, 2000).

The patentability of life

The biosciences have gradually been proposed also as a laboratory in which to verify and reinterpret the processes of reorganization of scientific research and of the more general ethical-political demands received from society. In particular, the basic demand that seems to emerge is whether an ethical-political rationality is possible that is not also a criticism of the market and in particular of the specific forms it has taken on in the industrial age. The debate on the patentability of living matter is an indicator of this ferment in that it underlines the difficulty of recording at the legal level the change in and the growing abstraction of the “form” taken on by the “commodity”, on which the “classical” political and economic theories. In a famous book written in the late nineteen sixties entitled ‘Gift Relationships’ (Titmuss, 1970), the

British researcher Richard Titmuss compared two alternative systems of donating blood in order to draw some significant implications in the field of public policy. The preferred system, the British and Red Cross one, was based on a “gift”, that is, on the gratuitous nature of the act of donating blood, unlike the American one, based on payment for the donated tissue. In demonstrating the superiority of the system based on the gift of blood tissue, Titmuss was convinced he had demonstrated also the superiority of the non paying system in healthcare policy, starting from its symbolical capacity to create a community. Nowadays blood donations account for only a small part of the tissues exchanged; in recent years they have seen the addition of stem cell banks, embryo collections and so on. Consequently, the gratuitous nature of the act of tissue donation may be followed by the creation of a subsequent economic value. All this has implied the shaping of a model in which the relations between science, law and politics are particularly evident and compelling, in particular with regard to the issue of the patentability of tissues, microorganisms and genetically modified organisms. The original thrust of patent rights has now shifted some distance to the conditions in which they are currently exercised. The protection of intellectual property as the “right to personality” related to the figure of the “romantic author-inventor” has now been dwarfed by the size and complexity of the technological and research investment apparatus demanded by biotechnological inventions: neither the individual character nor the moral interest, separated from its commercial interest, have survived in the industrial organization of patents (Boyle, 1996; OECD, 2002).

By simply rubber stamping the evolution of technology, the legal systems are at the mercy of the times, the directions and the methods of control of the technological undertaking, instead of representing a phase of critical reflection and of the establishment of guarantees addressing it. The long and fruitless controversies regarding the continuity or discontinuity between biotechnology and traditional forms of cultivation and breeding find a paradoxical

solution in patents: the patent is both the symbol of the novelty of the invention but socializes and guarantees the (also ethical) acceptability of the new know-how. One of the strongest criticisms of patentability in the biotechnological field is linked precisely to the extension of protection, and in particular the claim to exclusive ownership of the living matter: the patent rights actually refer to all the processes/products that contain the invention which, in the case of organisms, means all the subsequent generations. These powers of ownership of biological resources are having an effect on international relations between emerging countries and industrialized countries, again giving rise to situations of commercial colonialism. Moreover, they are liable to penalize rather than promote research and innovation, and to jeopardize fair access to certain medical and drug therapies. This is because it is increasingly unclear that the privatization of technological innovation and the drive towards technological innovation can maintain their complementarity and functionality unchanged.

Reconsidering the contract between science and society

The cultural and ethical significance of these issues is so great that the attempt to interpret them solely from the point of view of their technical and scientific complexity is reductive and misleading. Furthermore, it is clear that these are not issues of individual conscience but issues of collective ethical and political significance which modify the overall socialization processes, on the basis of which it is possible to define the relations and contexts in which to live and act, as may be summed up in the following three points:

- individual and phenomenology of everyday life (redefinition of one’s body, acquisition of new responsibilities and new physiological dependence);
- culture and value references (anthropological-cognitive limits versus a different experience world);

- economy, participation and governance of knowledge (transcending of industrial era);

Indeed the potential impact of the biosciences and their applicability over the next few decades will be comparable to the changes wrought by the development of electronics and computers in the second half of the twentieth century (Brent, 2000). The possibility of accessing this new knowledge can furthermore be followed by the creation of economic value that, as such, will increasingly become an area of competition in the distribution of resources at the global level and could widen the gap between rich and poor and between technologically advanced cultures and traditional cultures. In this sense the growing gap between the new global dimension of economic and political phenomena and, on the other hand, the uncertain hierarchy that exists between the main actors in this scenario and the limited nature, or rather, backwardness of the available analytical tools, contributes to widening the systemic crisis affecting and complicating the governance of the relationship between science, democracy and the welfare state, owing to the way the latter gradually developed over the 20th century. In other words, the biosciences tend to give rise to new political, economic and cultural hegemonies in countries and between countries which demand a redefinition of the set of rights of citizenship. To identify the relations among the mechanisms governing them implies the need to avoid giving any exclusively technical definition aimed solely at increasing the sectorial role of part of the scientific community and the elaboration of barren speculative explanations. Quite the contrary. It is a matter of identifying the elements on which it is possible to redefine the governance between science and society of the characters of transparency and responsible participation. In 2001 the European Commission published its White Paper on Governance (EC, 2001), which attempts an in-depth approach to the modalities of democratic participation in Europe. As far as the governance of science is concerned, the document calls for a process of democratization of the relationship between science and society.

This process passes through a two-fold need: it is a matter of extending consultation with the scientists and the notion of expertise, and to involve the man in the street in public decisions that are dependent on scientific knowledge.

The need to possess extended and pluralistic expertise is linked to various reasons:

- Mediation of the partial interests in view of a public interest in the presence of a profound redefinition of the interests and of the public/private divide itself;
- Capacity for a strategic view of longterm technological change and its social outcome, with special reference to sensitive issues regarding the welfare state;
- View of science itself as an integral public good, and therefore of public ownership and accessibility as a matter of principle and that can be directed solely towards longterm public interest;
- Communication of science as the *sharing of a (non proprietary) public good* using innovative channels, as above all the institutions themselves may be conceived to be in the knowledge society age.

The need for a fuller involvement of citizens in science-based decisions is linked to a renewed view of the rights of democracy (Funtowicz, 2001; Irvin, 2001). The considerable research dedicated to the understanding of science by the general public has shown that the growing reluctance of citizens to trust the experts' opinion and to accept their choices cannot simply be labeled as irrational but are linked to multiple, reasonable and concrete considerations (limited possibility of accessing pluralistic sources of information, lack of clarity in the criteria of experts' decision, possible conflicts of interest). In the ideas of 'scientific citizenship' or of 'citizen expert' two instances of integration of different knowledge and the redistribution of decision-making powers are merged. Although not being equivalent in terms of methodological validity, all the knowledge present in society must be compared in a pluralistic fashion as far as its credibility is concerned. This

means that: a) it is necessary to re-establish the connection between different disciplines that were so fragmentary that no dialogue is possible between them; b) it is necessary to set up the conditions of public accreditation for the various types of knowledge directed towards shaping social choices; c) the forms ensuring the public accountability of this knowledge must be identified. In other words, the demand arises for the social system to be enabled to develop a *civic epistemology* by means of which it can understand, evaluate and choose, which cannot be reduced and compressed so that it fits exclusively into the “scientific community”. The presence of this theme demands not an uncritical neo-positivism but an effort in the direction of the construction of analytical categories capable of absorbing and interpreting the new direction impressed on the process of civilization by scientific development (Jasanoff, 2005).

As shown both by the Iceland case and by the issue of the patentability of life, what emerges is a two-fold need. In the first place, the need to extend consultation with scientists; it is also necessary to achieve a higher degree of involvement of citizens in the science-based decisions having a direct effect on civil society by means of massive investments in the field of education. There can be no social control without the construction and socialization of a social knowledge proportional to the magnitude of the problems to be addressed: in Aristotle’s extraordinary words “the citizen is he who is capable of governing or of being governed”. In other words, the capacity to evaluate the opportunities and the choices not only in terms of their usefulness but also in terms of the quantity of freedom they produce, contributes to defining the confines of a just society.

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