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The Social Construction of Genetic Identities: A Research Note

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Abstract

This article is written as a research note, aiming to explore some contentious issues related to the emergence of genetic testing and the production of genetic knowledge. Adhering to the idea of a social construction of technology, the article discusses the co-evolution of social relations in health care and the emergence of new genetic testing procedures. Special attention is paid to the relationship between a convergence of technologies, resulting in the emergence of applied genomics, and the emergence of new identities, referred to as genetic identities. The article proposes to add to the idea of a social construction of technology that of a technical construction of society, identifying some major research questions and a methodology for research.

Introduction

The convergence of nanotechnology, genetics, cognitive sciences and informatics blurs the boundaries between scientific and social disciplines. Different kinds of information - genetic, cognitive, molecular and atomic - combine to create new data and knowledge systems. Applications of these data and knowledge systems are being developed in such diverse social domains as environment protection, energy production, water management, agricultural production and the development of weapon systems, while improvements in work-efficiency and learning, enhancements of individual sensory and cognitive capabilities, and advancements in creativity and human-machine interfaces are also envisioned (Roco 2001).

Technologies are to be considered as social practices. Firstly, this covers the idea that technologies are to be analyzed as socially constructed,comprising not only the artifact but also the labor divisions, knowledge systems, management practices and legal arrangements that make the artifact 'work'. The

social construction of technology (SCOT) approach (Bijker, Pinch & Hughes 1987) emerged in the 1980s, offering an alternative to instrumentalist and determinist approaches to the study of technology. Basically, SCOT takes a sociological approach to technology, and holds that technologies are concretized moments in history of people acting together. They are social products. Secondly, although technologies are to be considered as socially constructed, they also rearrange social relations. Technologies tend to produce their own distinctive forms of (hierarchial) authority and control, structuring identities and relationships.[1] Therefore, we propose to add to the idea of a social construction of technology that of a *technical* construction of society, as two sides of the same coin.

The focus of this article is on *applied genomics*. We will argue that applied genomics is socially constructed, but that the technologies it produces, in particular genetic tests, will, in the future, give rise to new identities. The article should be considered as a research note, exploring some contentious issues and proposing a research agenda.

Genetic Knowledge and Genetic Identities

Applied genomics emerged from the convergence of nanotechnology, genetics, cognitive sciences and informatics on the one hand, and high policy expectations on the other. In this convergence, the study of genes and their functions (genomics), molecular manufacturing (nanotechnology), cognitive sciences and information technologies are expected, among other things, to bring about a revolution in our understanding of the molecular mechanisms of diseases and the complex interplay of genetic and environmental factors, and to stimulate breakthrough discoveries in healthcare products by revealing thousands of biological targets for the development of new drugs, vaccines and DNA diagnostics. *One of the more visible products of this convergence of technologies is the genetic test*. Genetic bio-testers, which can have the size of a micro-chip, can identify the presence of genes in blood, saliva and other tissues, and generate data on actual diseases or health risks. These bio-testers can be analyzed as a technological practice, comprised not only of the device but also of management practices and particular modes of knowledge.

The genetic testing practice has raised a number of social issues. One of the most obviously important of these is that of *how people are to deal with the*

1 For a discussion of this, see Landon Winner, Techne & Politeia: The Technical Constitution of Society, http://www.umsl.edu/~rkeel/280/class/winner.html, access date 7-7-2006.

knowledge that results from genetic tests. Social scientists start to see the limits of an autonomy-based and informed free-choice approach. De Vries and Horstman argue that the emerging risk culture associated with genetic tests demands an ethics of 'how to live' (de Vries 2004). But the question of how to live creates moral obligations, and the creation of knowledge about 'the body' may lead to a deepening involvement of the body in the exposition of power. Prenatal diagnostic testing, for example, reveals knowledge about the foetus and may expose women to social pressure to abort a pregnancy, when it does not have the desired sex perhaps or risks particular deviances (the 'designer baby' issue).

If we define identity as concerned with the binding together of people, either by individual self-affiliation or as a result of categorization by others, as members of a particular group (Elwert 1997: 727), then *a genetic identity may be defined as the binding together of people on the basis of a particular genetic characteristic they share.* This gives birth to the hypothesis that new social-cultural realities may emerge when people organize themselves around specific genetic knowledge (Koot 2003: 7). The question is how 'genetic tests' and the production of 'genetic knowledge' is related to the development of 'genetic identities' and the corresponding new socio-cultural realities (Waldschmidt 2005; Stiker 1999).

Since genetic knowledge is produced in reference to a particular *genetic norm*, the binding together of people occurs on the basis of deviances from these genetic norms. In other words, genetic identities are formed on the basis of a risk of a particular genetic trait determining one's potential susceptibility to a particular disease. Labeling theory, therefore, may offer an important contribution to the understanding of identity formation and the creation of new socio-cultural realities (Hughes 1971). Although more a cluster of related ideas than a unified approach, the common denominator of labeling theories is that deviance is not just a set of characteristics, genetic characteristics in this case, but must also be seen as a process of interaction. In other words, labeling theory may help us to understand how deviance from genetic norms is produced and what this says about social relations in society (Giddens 1989: 129).

A central question is that of how the social construction of genetic knowledge and the technical construction of genetic identities operates? In order to investigate this and related issues, three sets of research questions must, it is suggested, lie at the core of any research agenda.

1) *How and to what extent do converging technologies contribute to the construction of genetic identities?* Advances in nanotechnology, genetics and informatics have already resulted in a rapid increase in the development and production of new genetic diagnostic tests. Genetic tests are one of the most direct encounters with genetics that people can have, and may be the reason for the construction of genetic identities (Zwieten 2004; Rose 1984).

2) *How and to what extent do genetic norms influence the construction of genetic identities?* And additionally, how do the testing technologies (biotesters) both *reflect and produce* particular social norms? Self-perception based on genetic information gives a new dimension to processes of normalization, which is a social process of conforming to certain social standards or rules. Knowledge about genetics is a new social product, one which reveals and sets a unique standard, that of a normal (normative) genetic constitution. Genetic norms define what is considered genetically 'normal' and what is consequently considered genetically non-normal (and thus, by implication according to normative logic, abnormal or flawed). This genetic norm is a new player in the landscape of normalization (Waldschmidt 2005; de Vries 1997; Folter, 1987).

3) *What is the role of actualities and potentialities in the construction of genetic identities?* And additionally, under what circumstances are people able to develop their own 'coping mechanisms'? New genetic identities can be based on genetic information that is directly related to an actual experience, such as a disease that is present in the body. However, genetic identities can also be based on potentialities. People who experience their bodies as perfectly healthy can stumble upon genetic information that tells them otherwise. Genetic tests can reveal risks and potential diseases that contradict the way people have been experiencing their own bodies up to that time (Horstman 1999; Zwieten 1999). This can lead to the development of *technologies of the self* with which people can resist this contradictory knowledge and which they can use in the social process of (re-)constructing their genetic identities.

The practice of genetic diagnostic tests

A main research object is the practice of diagnostic genetic testing. The convergence of nanotechnology, informatics and genomics offers an increasing number and variety of diagnostic genetic tests, tests which are able to reveal information about the genetic constitution of people, including unborn children, and might offer new cures for diseases and remedies for disabilities.

This information can also shape identities, as indicated above, by indicating the risks of developing a certain disease or disability, which relates to potentialities, about what the future might reveal. Information is also being generated about actual relationships between behavior and genes. Various scientists claim to have discovered genes related to features as varied as autism, schizophrenia, alcoholism, depression, criminality and loneliness (Kelsoe 2004; Huijer 2004).

The testing practice involves a wide spectrum of factors that can influence the construction of genetic identities, at both individual and institutional levels, including policies and procedures regarding which tests to develop and which tests to allow on the market, choices about which tests to take, and decisions about which test results should be given to people, including choices about informing family members and other parties. Therefore we take the diagnostic genetic testing practice as a focal point (Horstman 1999; Zwieten 1999).

Diagnostic genetic tests are increasingly available to the public outside the environment of hospitals or clinical genetic centers. Genetic information is starting to penetrate the lives of people and have effects on how we perceive ourselves (Houten 2005; Steensel 2002; Pfeiffer 1994). For example, the company MediChecks.com sells over a hundred different kinds of genetic tests to the public through its internet site. These can determine risks for contracting a range of conditions, such as deafness or a severe disorder like Duchenne. The tests are often cheap and easy to administer - no more difficult, in fact, than putting a piece of cotton inside the cheek.

Sales are skyrocketing and company leaders speak of 'empowering people with knowledge'. Indeed, genetic tests may help people to explore their genetic constitution and to shape genetic identities about themselves. Tests can be used to create knowledge about the genetic self and potential disorders preventable by medical technologies. However, diagnostic genetic tests may not arouse undiluted enthusiasm. Conflicts between the will to know and the will to not know may arise. Knowledge resulting from genetic tests (about actual and potential risks) is able to change self-perception (Hillekens 2003), but also exposes people to power over their bodies and very being.

The increasingly important role genetic tests play in shaping identities takes place not only against the background of a 'care for the self'. New political landscapes are being shaped around genetic technologies. Companies are starting to realize the potential of genetic screening. In the US at least five of the Fortune 500 companies conduct genetic screening on their employees. The

number of people being stamped 'sub-standard' or a 'bad risk' for the company is increasing. As a consequence, people with certain genetic traits encounter difficulties in getting good insurance and finding jobs. Campbell speaks about the government of disabilities (Campbell 2005).

Focusing on the diagnostic genetic test leads us to define two groups of research subjects. The first group consists of *institutions* that are involved with the production, processing, informing about and regulating of genetic tests. This group will provide insights into the construction of genetic norms and the role of the convergence of technologies in the production of genetic tests. The second group consists of people that have been or are the subject of genetic tests. This will elucidate the role of actual experiences and potential risks in the genetic identity construction process. The ideal-types of medical, social and transhumanist identities can be used to identify people and organizations with different perspectives on genetic norms.

Medical, social and transhumanist ideal types

Knowledge is 'produced' and 'processed' differently in different social groupings. To study different ways in which genetic knowledge is 'produced' and 'processed', the concept of an ideal-type may be useful. A concept originally developed by Max Weber as a research instrument (Weber 1949), an ideal-type is an analytical construct consisting of the accentuation of several points of view and concrete individual phenomena. Weber saw two problems that a social scientist is confronted with when choosing research concepts. The concepts can be too general, or too particular. Weber developed ideal-types as a measuring tool to study similarities as well as differences, a tool that can be used as a method for comparative study (Hekman 1983).

Gregor Wolbring introduces three ideal-types related to disability perspectives on science and technology: the *medical, social and transhumanist type* (Wolbring, 2003). These ideal-types can be used to abstract three kinds of genetic identities, with a focus on research subjects that can each be situated as closely as possible to one of these three ideal-types. The abstraction of genetic identities using ideal-types enables a comparison of the genetic identities that people and organizations construct.

The *medical ideal-type* represents a mostly medical perspective on the self. People and organizations favoring this type will look at technological and medical developments as ways to improve their quality of life. New knowledge about their genetic constitution will fit into this medical perception. This

knowledge can be used to create new possibilities to increase quality of life and prevent unwanted future problems.

The *social ideal-type* represents the perspective that problems can mostly be solved with social solutions. People and organizations favoring this type will look at social constructions and political relations as the source of problems and the possible solution to these problems. They will resist knowledge about genes as it transfers social problems to individual medical problems. For example, research into genes for criminality or intelligence will make low intelligence and criminal behavior individual medical problems, and remove them from the social domain.

The *transhumanist ideal-type* represents the perspective that every person is disabled and in need of improvement. Science and technology need to be fully utilized in order to create possibilities for enhancement, even beyond the normal human condition. Information about genes will be used as much as possible to develop improvements (Wolbring 2005).

Genealogy

The concept of ideal-types provides us with three categories of research subjects, the medical, social and transhumanist ideal-types. When we combine this with Michel Foucault's genealogy concept, with its three axes of truth (knowledge), power and ethics (care for the self), we can compare how social groupings construct genetic identities.

Foucault defines the genealogical axes as first, a historical ontology of ourselves in relation to truth through which we constitute ourselves as *subjects of knowledge*, in this case genetic knowledge; second, a historical ontology of ourselves in relation to a field of power through which we constitute ourselves as *subjects acting on others*; and third, a historical ontology in relation to ethics through which we constitute ourselves as *moral agents* (Zwart 1995; Visker 1990; Foucault 1980).

Although Foucault himself does not provide a ready-to-use toolbox that can be applied in any field of interest (Karskens 1995), the genealogy concept does provide three ways of looking at the genetic testing practice, with various perspectives on truth defined in relation to genetic testing. In respect of truth, several organizations express powerful truth-forming abilities related to genetic tests and genetic norms (Bal 2002). Individuals also construct personal conceptions of truth about genetics. What do genetic tests reveal about our bodies,

or the bodies of others? What kind of truth is a genetic test able to reveal, what conceptions about normality, disease and flaw are assumed as part of the test?

The power axis can be used to study power relations. Genetic testing is produced in a complex field of power relations. There are, for example, companies that want to produce new tests and get them adopted into regular screening practices. Governments try to stabilize the costs of the medical system, and will be forced to make economic decisions about new genetic tests. Then there are various patient organizations that are in favor of certain tests, or resist certain other tests.

The ethical axis can be used to explore how people and institutions will develop their own ethics regarding the use of genetic tests. Ethics is concerned with the views on life of people or institutions, for example, views on what it means to be healthy or to be a valued member of society.

This ethical axis of the genealogy concept contains Foucault's work on technologies of the self. For Foucault, technologies of the self constitute one of four types of technologies. Technologies of the self never function entirely separately from the other types of technologies, so it is worthwhile, therefore, to understand the position within these other types of technologies, of the technologies that people develop in relation to the genetics apparatus. Foucault describes the four types of technologies as: '(1) technologies of production, which permit us to produce, transform, or manipulate things; (2) technologies of sign systems, which permit us to use signs, meanings, symbols, or signification; (3) technologies of power, which determine the conduct of individuals and submit them to certain ends or domination, an objectification of the subject; (4) technologies of the self, which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality' (Foucault 1988; Martin 1988; Foucault 1980).

Genetics apparatus

Foucault's genealogy concept describes three axes for the study of the construction of genetic identities. His notion of an apparatus is also useful for studying the relations between these three axes of truth, power and ethics. Foucault describes the elements of an apparatus as

> *'...a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions*' (Foucault, 1980).

We propose considering genetics as an apparatus, a genetics apparatus. Many of the elements of an apparatus are present in the field of genetics: there are scientific discourses on genetics, genetic counseling institutions, and research institutions specifically focusing on genetics; we have the DNA double helix as an architectural form; some laws on genetics are already in place, dealing, for example with the use of DNA in solving crimes; and there is a strong moral imperative to be genetically normal (Morgan 2005).

At the heart of the genetics apparatus discourses on genetics are those that determine how truth is formed, through the workings of power. The key to understanding power relations is to identify, contextualize and understand the institutionally mediated mechanisms that render the diffuse and complex day-to-day micropolitics intelligible. These mechanisms are implemented through various technologies of production, and are considered by Foucault to be dynamic points of intersection for the production, transformation and manipulation of things and individuals.

The ideal-types help to identify various positions people can hold, while genealogy helps to refine the examination of how genetic identities are constructed. The genetics apparatus can be used to connect the results and define relations between the genealogical axes to provide a more overall perspective on how genetic knowledge effects society, and how it gives rise to the social construction of genetic identities.

Conclusion

Against the background of a widespread development and application of genetic technologies within the context of scientific ambitions, corporate investments, political decisions and moral evaluations, it is proposed to analyze trends towards the production of genetic identities and socio-cultural grouping. The approach discussed aims to contribute *to a theoretical understanding of the relationship between technology-development and identity-construction.* It has been suggested that genetics testing will not only contribute to the production of genetic identities and socio-cultural groupings based on these identities, but also to the exposure of subjects (classified and grouped on the basis of genetic knowledge and identities) to power over their

bodies and being. This will contribute to a thorough understanding of the relationship between the development of new technologies and the production of knowledge, the formation of identities, and the exposure to power, an understanding which is relevant for a wide range of stakeholders, ranging from researchers, policy-makers and politicians to self-help and disability groups. This new approach aims not only to show how 'flawed' genetic identities are constructed, but also how people develop particular coping mechanisms (so-called 'technologies of the self') which help them to resist the exposure to power fostered by the production of knowledge about their genetic selves.

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