

PERCEPTIONS OF THE HUMAN GENOME PROJECT AMONG A SAMPLE OF CHILEAN COLLEGE COMMUNITY*

PERCEPCIONES DEL PROYECTO GENOMA HUMANO EN UNA MUESTRA DE UNA COMUNIDAD UNIVERSITARIA CHILENA

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ABSTRACT

During the years 2001-2002, we conducted an investigation regarding Chilean undergraduate students' and professors' perceptions of the human genome project. We interviewed 50 male and female undergraduate students from five faculties (Science, Social Science, Philosophy, Arts, and the general Bachelor program), 10 academics, and conducted 10 focus groups among students pertaining to the same academic units. In this paper we will discuss the results of this investigation in order to answer four questions: what the human genome project means to the interviewees, how they got their information about it, what consequences it could bring, and what should be done with this knowledge.

KEYWORDS: Human Genome, Latin America, Social System Theory, Risk.

RESUMEN

Durante los años 2001-2002, realizamos una investigación acerca de la percepción de estudiantes universitarios y profesores acerca del proyecto genoma humano. Entrevistamos 50 estudiantes universitarios de ambos sexos de cinco Facultades (Ciencias, Ciencias Sociales, Filosofía, Artes y Bachillerato), entrevistamos 10 académicos y condujimos 10 grupos focales entre estudiantes de las mismas unidades. En este artículo discutimos los resultados de esta investigación en orden a responder cuatro preguntas: qué significa el proyecto genoma humano para los entrevistados, cómo consiguieron información al respecto, qué consecuencias traerá y qué debemos hacer con este conocimiento.

PALABRAS CLAVES: Genoma humano, Latinoamérica, teoría de sistemas sociales, riesgo.

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INTRODUCTION

We propose the concept “genetic communication” to refer to all the social communications referred to the new genetic discoveries, as long as they enter as communica-

tions within a social system. They include beliefs, thoughts, information, expectations and any other topic around this project, either generated by scientists, journalists or common people. Because we define genetic communication as a social construction, the validity of its contents is not of great importance to us, given that their statements acquire reality through the distinctions that produce them and their importance consists

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in people, as well as social systems, act according to these distinctions or forms.

Our epistemological assumption is that society self-contained their own descriptions, explanations, and interpretations within their own communications, i.e, society can be seen as a system formed by communications produced from differentiated systems (Luhmann 1998), and that the second order observation (Arnold 1997) is the way to get access to them.

We assume that genetic themes get their form in social reality when they diffuse as knowledge in their communication because: in what other way we can know about it? According to our perspective, we deal with “sociocultural bioartifacts” because neither Dolly nor the SOX2 gene describes itself! Although naturalists insist in saying that to discover is to develop something that pre-exists, they also assume that genes existed before they were known. Here, we argue that something does not exist in society if that something is not known to them, all of which can be observed in their descriptions. For example, if any given society has not heard of the concept of *cancer*, then for them cancer is not known there and doesn't exist.

Taking the above into consideration, genetic communication can be documented because all this information can be expressed by language.

Our research was guided by the following questions:

- a) Which topics of communication do students and academics of the University of Chile relate the new advances and discoveries from the Human Genome Project to?
- b) Which ones are the sources of information that students and academics of the University of Chile use in order to be informed about the Human Genome Project?
- c) Which ones are the consequences that students and academics of the University of

Chile anticipate about the new advances and discoveries from the Human Genome Project?

- d) Which ones are the regulative actions that students and academics of the University of Chile propose about the new advances and discoveries from the Human Genome Project?

Our own purpose is to make a contribution in the discussion about how Latin American people create social answers to the questions proposed by the new bio-scientific technologies. It is possible to think that Latin American public opinion could vote against or in favor of such technologies based more on beliefs than scientific knowledge, even considering a population of university students from which this study takes its data.

MATERIAL AND METHODS

Due to grant's restriction, we choose The University of Chile because of the advantages we had to interview students and professors while we, the authors, work on the campus. This situation could be put into perspective if we consider the fact that it is one of the main universities of the country and internationally one of the most prestigious, holding a great diversity of students from different backgrounds (class, ethnicity, place of origin, etc.).

In order to obtain a wide range of data within The University of Chile, we chose one campus holding five faculties: Science, Social Science, Philosophy and Humanities, Art, and the General Bachelor Program. Within each faculty, we randomly chose ten students to interview from any year, covering every career of that faculty, with the same proportion of male and female (50 students in total). We then conducted 10 focus groups (two for every faculty) with groups from six to nine students each and from every year

or career of that faculty. Finally, we randomly interviewed 10 academics (two for every faculty of various departments). All the subjects were Chilean in nationality.

The interviews used were open, took about thirty minutes and covered all the four research objectives. The focus groups took about an hour in length. They all were recorded and typed. Then, every file was formatted for its use in the Ethnograph 5.07 software for content analysis.

The methodological approach considered for this research is qualitative, which implies the search for meaning (Hammersley 1994, Taylor 1986) as opposed to measurements of a variable such as “there is/there isn’t” or “more than/less than”. The answers are considered symbols which transport meanings or values. The purpose of the content analysis is to collect all those meanings, which, as a system, create a “genetic communication”, as we define it earlier. Therefore, this is not a statistical analysis leaving some symbols outside the normal curve. This perspective embraces them all, showing us what people, in a specific moment of time and place, think about genetics. The same applies to the focus group, a technique defined as social discursive practice (Canales 1995) which allows us to grasp meaning among a group of individuals in a social context.

The data was split among the team for its first processing in the computer software. Every file was integrated in a single one for students, one for academics and one for focus groups. Then, in order to cross-check the analysis, the five members of the research team work together in the final meaning of the symbols used by the informants.

RESULTS

Each of the four objectives will be presented, specifying the source when appropriate (students, academics, gender, faculties).

a) The Topics of Communication

To start with, very few people were able to give a precise definition of the human genome (except for science students and academics, as could be expected), although everyone without hesitation related the concept to the science discipline. For our subjects there are two main meanings of the human genome. The first one can be summarized in the phrase “it’s about genes” and the second one in “it’s something like...”

The first group of people talk about genes, units of information, chromosomes, and the like, using a technical vocabulary to specify what the human genome means to them: basically a branch of contemporary scientific research.

The second group cannot give an exact definition, so they say “it’s something like”: a helix, phone book, structure, map, instruction manual, data base, alphabet letters, heritage, data, code, world map, keys, bricks, and patterns.

This group also relates other ideas about the human genome research: It is not so relevant to the third world, but a topic of the first world. It can help to avoid and cure illnesses, it can help to improve our quality of life. It modifies human nature (either in positive or negative terms). It is almost secretive, a closed domain of highly specialized academics. It is basically cloning, like Dolly. It is problematic with religious beliefs, because man is trying to play God. It is only a technological sphere of science, and it does not create new theories, axioms, or concepts. It is a discovery, not an invention. It is million dollar business.

Taking wider approach now, most of the subjects say they have never considered the implications of the human genome project. They consider it something distant from their daily lives or associated to the future. That is not to say it is unknown. Their information gap has been filled with science fiction, through literature, comics, and mov-

ies. They usually mention Isaac Asimov, Jules Verne, George Orwell and mainly Aldous Huxley's *Brave New World*. In movies they cite *The Fly* (1986), *The Island of Dr. Moreau* (1996), *Alien Resurrection* (1997), and *Gattaca* (1997).

Their opinion about the project can be grouped in three types: positive (mainly science students and academics), negative (all the others), and indifferent (science students and academics). The first type says it's wonderful, perfect, a gift of nature, and the like. The second type says it's scary, against nature and God, there will be problems controlling this knowledge, and their consequences are unpredictable. The third type says it's an early stage of a technological research, not science. For example, talking about the origin of life, some say it's a biological process and others a divine act. The subjects with negative opinion think no human being can make a decision about who can be born or with what characteristics. Every human being is unique and there resides its nature, also chance is a natural condition not to be altered.

All the subjects make a distinction between the scientific knowledge about genetics and the biotechnology applied to human problems. They say science creates the knowledge which is used by technology. The role of scientists is to discover and, therefore, they are released of responsibility. Science as itself is not restricted by ethics, although its applications are. The applied knowledge, they say, is always intentional, causing good or bad consequences, depending of the way the information is used. For them, technology allows mankind to improve the quality of life and solve problems, but at the same time it creates others which have to be regulated. The question is: how can human beings rightly apply these findings?

Almost everyone agrees that the Human Genome Project is not a Third World priority. It is something carried out by a few coun-

tries, which restrict the possibilities of other countries to make decisions or take actions about it. Even within the country, the more powerful groups could gain access to this technology, excluding the remaining population. Therefore, the topic of development and underdevelopment is related to the topic of access to the knowledge of the human genome. Those who control that information will increase their power. For this reason, it is not desirable that a country or enterprise could establish a commercial patent of the results, because it belongs to humankind and it is a world heritage.

b) The Sources of Information

In theory, because our subjects are members of a college community, they are in better conditions to access information about the recent developments of the Human Genome Project. Nevertheless, they declare to have no expertise and their knowledge level can be described as superficial and very general.

The main sources of information used by the subjects are the mass media, mainly television, watching evening news, scientific programs and the Discovery Channel. They also mention newspapers, magazines (either scientific or commercial), the Internet, radio, and books. Another source is the information obtained from class (either school or university), assignments, friends or family members.

Many interviewees feel they do not have a superior knowledge of the human genome because of the following reasons: lack of interest, the information that exists is scarce and restricted to few specialists (researches and their funding groups), and there is a problem in making this knowledge accessible to common people given its highly technical language. Furthermore, the media could distort its content because of some interests of powerful groups.

c) The Consequences

The subjects identify lots of future consequences (women usually identify more than men). If there are consequences, they would unlikely experience them in their life times.

They classify the consequences in the good and the bad ones, which can be seen mainly in three topics: genetic therapy, cloning, and transgenic food.

The subjects differentiate four types of genetic therapy: somatic (treatment of sick cells), germinal (avoiding the transmission of heritage illness), perfective (manipulation of genes in order to improve certain characteristics), and eugenics (search for some qualities like intelligence). This last one is the most mentioned, the most questionable, and considered a bad consequence. The other three are highly valued, as long as they do not turn into a search for perfect human beings. Cloning is one of the first consequences seen by the subjects, either about organs for transplants or whole individuals (this last one seen as bad). Dolly sheep is the symbol most mentioned of this idea. Finally, transgenic food is seen as a good consequence of genetic manipulation if it is capable of abolishing Third World hunger.

Another consequence regarding the Human Genome Project is that it could change our definition of humankind, create different types of citizens allowing discrimination in access to work and health, and break the natural balance of life.

In a more general outlook, although the subjects limit genetic research to science, they all agree that their consequences go far beyond science and into almost every sphere of social life. They worry about the use of genetic research not reaching poor or sick people but instead market forces redirecting this knowledge into the private health industry (i.e. aesthetics, plastic surgery, etc.). Most of the subjects relate the Human Genome project with the economic system of

society, which in turn modifies the consequences of the project.

Collateral effects could be the increasing world population, alteration of food or animals that could be dangerous to humans, experimenting with humans that could die in order to test vaccines, and the erasing of individuality as long as it makes serial people like factories. In this case, some even fear the same thing can happen with the Human Genome project as with the nuclear bomb (a scientific experiment that became used as a military weapon and eventually became a human disaster).

d) The Regulative Actions

Basically, the information could be grouped in three main topics: who must regulate, how to regulate, and other related ideas.

Who must regulate

There is no single answer to this question, but all the subjects have an opinion about it: the public opinion, individual consciousness, scientists themselves, investment companies, governments of the countries where the project is carried out, a council of experts, society as a whole, the United Nations, and universities.

Although the opinions are diverse, they can be divided in two main groups: those who say that scientists are the only ones who can regulate, and those who say that this responsibility cannot be given exclusively to them, being part of that action other social units. The argument for scientists is that they are the ones who know about it, and science has its own control mechanism that regulates its practice. The argument against it is that the effects of the Human Genome Project go far beyond science and must involve society as a whole or its representatives.

How to regulate

The people in the study give the following answers as how the genome project can be regulated: using the law (either existing or creating new ones), educating the population, creating an assembly of experts, generating public debate, and applying bioethic principles. Again, most people think that either science has its own way to regulate the project or other protocols have to be implemented in order to control it.

Related ideas

Another opinion expressed by the subjects is that there is no need for regulation. If the knowledge is stopped before being used, there is no need for regulation. But, in another sense, some subjects say we don't have to regulate in order to let the project show us its full potentialities. Regulation, for some interviewees, limits creativity, which it is not desirable as a scientific principle. Others argue that knowledge cannot be regulated, but the uses have to be. Finally, some say we don't have to regulate now, but we should wait to see what will happen in the future.

Other topics about regulation is that the Catholic Church must play a role defending human rights, that every country must specify its own rules (although an international guidance is also important) and that technology has to be become humanized.

CONCLUSION

In conclusion, when summarizing the point of view of the students and academics interviewed, it is both suspicious and reluctant. They perceive themselves as uninformed, with different expectations, with many fears about the application of the knowledge from the biosciences, and a feeling of impotence about its uses, which could be controlled by

interests they do not know of. They think that a humanity altering the natural processes, through genetic manipulation, is not prepared for such responsibilities, with ethical implications at sight. Nevertheless, complexity does not paralyze. They construct their limited and contradictory knowledge upon confidence or ignorance under systems of sense that reduce the complexity of the genetic research and its applications.

From our point of view, the information around the effects of genetic research create emergent problems, although the risk is not found on the latest information about the Human Genome Project, but on the cultural, political, and economical implications that walk alongside their knowledge and uses in all levels of human life.

The source of genetic communication, and their risks, dangers, and expectations, are composed of mainly research centers, universities, corporations, companies, public institutions, NGO's, protest movements, consumer associations, opinion leaders, and expert groups. The mass media broadcasts their arguments, amplifying their effects on the public opinion, governments, communities, and families, who then return the information to the media. This system of communication produces and reproduces a social memory about genetic communication in this population of Latin America.

As anthropologists, we hope this paper can be used for comparative purposes about the influence of biotechnologies in Latin America and their cultural effects on its people.

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