

# Conceptions on genetics in a group of college students

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**Abstract** The purpose of this study was to investigate awareness, beliefs, and opinions on genetics in a group of Brazilian college students from several courses. The study used the focus group technique with the participation of 19 students, divided into four groups. Also, it used the isotopic reading technique to analyze the material. The results were divided in four themes: the basic knowledge of genetics, the “new genetics,” including molecular biology and testing, genetic manipulation, and genetics and the media. The participants showed reasonable knowledge on the subject, obtained from various sources, including the printed press, the internet, documentaries, and fictional TV shows. Ethical issues were discussed comprehensively and the groups showed awareness on the hazards brought by genetic reductionism and the need to have some type of regulation regarding genetic manipulation and testing. It is necessary to broaden the debate about the progress in genetics because some of them will affect a significant number of people. This debate should include the lay public, which has been actively participating in decisions involving research and the use of new technologies.

**Keywords** Genetics · Public opinion · Education · Focus groups

## Introduction

The improvement of molecular methods and genetic mapping strategies is rapidly increasing the number of diseases with

mutations described, with thousands of tests to detect genetic variations available or under development stage (CDC 2012). Many areas of medicine and public health will benefit from this knowledge in the near future, through improvement of existing preventive measures. The translation of such technological advances in practical attitudes, leading to action and prevention, will have a greater impact on public health if there is an ecological approach to health promotion, with strategies implemented at multiple levels: individual, organizational, community, and political (Petersen and Bunton 2002; Lanie et al. 2004; Wang et al. 2005). While these benefits are still a promise for most diseases, public health practice must establish priorities to address human genomic information to improve population health, providing information about new technologies, implementing evidence-based applications, and discouraging the use of unvalidated applications (Khoury et al. 2011).

The assistance to potential users of new technologies should be done by qualified professionals to provide proper information and guidance on genetic diseases and related procedures (Asai et al. 2004). The proper guidance so users can make informed decisions about their health becomes clearer when the professionals are aware of public information and concerns on the subject (Wang et al. 2005). The educational activities that take into account prior knowledge are the most effective ones (Lanie et al. 2004), and it is possible that strategies focused on providing relevant information, linked to doubts and public concerns about genetics, may be more successful than formal education alone (Wang et al. 2005).

There is little information in Brazil about public awareness and opinion on genetics. This scenario has been changed by recent works, such as the one by Massarani and Moreira (2005), with high school students. This paper highlights the interest in genetic issues that are emerging in the general public, whose need for knowledge cannot be met by formal education only—much information on this matter

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comes from the press, which usually covers it superficially and partially. Yet, the public shows critical ability to absorb and filter the information (Massarani and Moreira 2005).

Recognizing the importance to know public opinion on genetics and the scarcity of data in this area, this study was conducted. The purpose was to obtain information regarding the awareness, beliefs, and opinion on genetics in a group of college students.

## Methodology

The study included Brazilian college students from Rio de Janeiro, from several courses. The participants were chosen by convenience and the meetings took place in their college or training place. The choice for college students aimed to ensure that participants had had contact with basic genetics in high school, which, in Brazil, has a mandatory minimum curriculum content for all students, including fundamentals of genetics.

The groups' moderator was a specialist in medical genetics, who proposed issues for discussion (basic genetic conceptions, metaphors for DNA, genetic determinism, genetic tests, genetic manipulation, birth defects, and sources of information) according to a preestablished script (Table 1). An assistant followed and took notes of the sessions, which were recorded, transcribed, and analyzed. Each participant received a number from P1 to P19, used to identify him/her in quotes

throughout the text (Table 2). All group sessions were conducted in Portuguese, and later a free translation into English was made, keeping the original meaning of the phrases.

The methodology of focus groups (Krueger 2004) was selected as it enables to observe the attitudes, beliefs, and reactions of a group in a way that would not be possible using other methods (Gibbs 1997; Krueger 2004; Bates 2005). Thus, the researcher receives lots of information in a short period of time. This method is proper to the goals and is useful if there is interest in the use of language and culture of a particular group and to explore the level of consensus on a particular topic (Bates 2005).

The technique used to analyze the material was what the Russian semiotician Algirdas Julien Greimas (1987) calls "isotopic reading." Isotopics are redundant semantic categories that enable the uniform reading of the text. With the support of isotopic semantic categories, the study passed from micro-semantic, the isolated meaning of each phrase or statement, to macro-semantic, the whole speech meaning. This passage is carried out in three steps: first, the comparative study is made on parts that contain text, discovering their underlying meaning categories; then, they are isolated from the categories that repeat themselves, the isotopic categories; and finally, these categories are distributed by semantic levels of speech: figurative, thematic, and axiological.

The figurative level is related to the perception of the real world, often alluding to one of the five senses. The thematic

**Table 1** Script used for the focus groups

1. What comes to your mind when you hear the word genetics?
2. Concepts about DNA, chromosomes, genes, and mutations
3. Metaphors for DNA: fingerprint × recipe  
Cartoons shown as illustrations
  - (a) DNA molecule and a fingerprint
  - (b) Recipe → cookies/gene → protein
4. The role of the genes in the determination of physical and psychological characteristics and disease  
Cartoons shown as illustrations:
  - (c) One scientist to another: "Frankly I'm a bit confused. According to the genetic printout, this gentleman is, in fact, a goat." (available at <http://www.cartoonstock.com>, search ID for0083)
  - (d) Man to wife in car, completely lost in an empty road going uphill: "Because my genetic programming prevents me from stopping to ask directions—that's why!" (available at <https://cartoonbank.licensestream.com/LicenseStream/Portal/index.aspx>, image ID 15163)
  - (e) Man in court, being judged: "My DNA made me do it." (available at <http://therealsasha.wordpress.com/2011/08/26/free-will-determinism-and-moral-responsibility/>)
5. What is the meaning of having a mutation for breast cancer (for example)?
6. Genetic tests: what are they used for, what they inform, when they must be made?  
Cartoon shown as illustration:
  - (f) Ms. Tena, reader adviser, is standing in front of her shop. Next door is her competitor, Madam Rosa, geneticist. (Downes N (1987) *Science* 238, Nov 9, p. 772)
7. Manipulation of embryos and cloning—concepts and opinions
8. Birth defects—causes, frequency, and prevention
9. How do you get information about genetic concepts and new findings in genetics?
10. Is there something else you would like to add or comment?

level is the one which the figurative elements are grouped in themes, and the axiological level is where the oppositions and the opinions of value that the text may bring are identified (Greimas 1987; Cardoso 1997, pp. 172–174).

## Results and discussion

There were 19 participants, between 18 and 29 years old; 11 of which were women, from the courses: linguistic, pedagogy, psychology, chemistry, chemical engineering, food engineering, and training of merchant marine officers. These were divided into four focus groups with four to six components each (Table 2), and one meeting, lasting about 1 h, was held with each group.

The opinions verbalized in the focus groups meetings were classified into isotopic categories, organized under four themes: the first, called “the content of genetics,” refers to basic knowledge of genetics, the second refers to the so-called new genetics, including molecular biology, genetic testing, and the prevention of birth defects, the third isotopic category is related to genetic manipulation, and the fourth to genetics and the media.

### The “content” of genetics

When the participants were asked how they felt by hearing the word “genetics,” the words “DNA” or equivalent such as “double helix” were immediately mentioned by everybody, as well as “heredity.” The basic concepts of genetics mentioned, such as chromosomes, nucleotides, and common genetic conditions are often related to what participants had heard at school. There were also references to daily life and TV shows. Technical terms were used naturally, either by remembering classes or by contact with the subject in daily life. This familiarity with concepts and terminology of genetics, acquired from multiple sources is described by several authors (Nelkin and Lindee 1995; Lanie et al. 2004; Bates 2005), which also calls attention to an educational gap in this area, as education is not enough to deal with practical applications of basic science (Lanie et al. 2004). The complex structure of molecular phenomena,

with a multiplicity of levels involved, is particularly challenging to understand (Venville and Treagust 1998; Duncan and Reiser 2007). It was possible to detect inconsistencies and doubts when groups went further on the subject, as in this discussion:

“There are chromosomes *X* and *Y*” (P1)

“Is the chromosome in the DNA?” (P2)

“There is *XX* ...” (P3)

“No, this is in the ... *X* and *Y* are in the chromosomes.” (P1)

“There are 26 chromosomes ... Adenine only binds to thymine, something like that!” (P3)

“But is DNA actually placed in the chromosome?” (P1)

“I don’t know.” (P3)

“Is there any difference between DNA and RNA?” (P5)

Or in the examples:

“My cousin’s grandparents are cousins and, among his mother and aunts, one is a dwarf. And my cousin was born with a huge birth mark. I think it was because of the union of his grandparents, who are related.” (P5)

“I had a cousin with a genetic disease. Every odd child will have this disease. My aunt had the first child, which had [the disease], the second did not have and the third did.” (P10)

“Even identical twins will have something, some different recessive allele.” (P11)

During the discussion, some cartoons related to the two of the most used metaphors to describe the DNA were shown (Condit and Condit 2001; Lippa 2002; Rovira 2008): a fingerprint and a recipe. The fingerprint metaphor was preferred by most, as DNA was described as “unique,” “unchangeable,” and “specific.” Also, the legal use of DNA as being similar to fingerprints was brought up.

The recipe metaphor is considered to be easy to understand and useful to explain DNA functioning in a non-reductionist way (Condit and Condit 2001), conveying the idea that heredity is not destiny in the deterministic sense, and that complex recipes can lead to unexpected results, by the multiple variables involved (Lippa 2002). This perception arose in a group where the following dialogue took place:

“DNA is several little factors that combined shapes what you are. It is like a cake recipe, if you switch milk with orange you get an orange and not a vanilla cake.” (P11)

“I prefer the fingerprint because it is unique.” (P14)

“Who says all cakes are the same?” (P12)

“Depends on the recipe, on the oven...” (P11)

“I also like the cake metaphor. If you take something out, change the way you mix it, the result is different.” (P13)

**Table 2** Composition of the focus groups

Group 1—P1 to P6—all merchant marine officer students
Group 2—P7 to P10—all pedagogy students, except P9, a linguistics student
Group 3—P11 to P14—all psychology students
Group 4—P15 to P19
P15 and P16—chemical engineering students
P17 and P19—chemistry students
P18—food engineering student

“And this is basically what makes us different from each other.” (P12)

“If the cook was sad, it comes out different than if she was happy.” (P11)

In another group, during the discussion on the cause for congenital malformations, P2 also used the recipe metaphor, explaining the variability and exclusivity of the genome of each individual:

“Every person born is a cake recipe that has never been tested before. Part of these recipes fails and people are born with problems.”

In discussing the influence of genetics on human traits, all were concerned to point out that no one can be defined only by their genes, and even twins with identical DNA have their individuality. Likewise, “to have a gene for a given disease/trait” was interpreted by the group as having predisposition to a certain disease or trait. The subjects also believed that the expression of such gene could be mediated or even prevented by the environment and by personal attitudes. But there is a concept that more specific traits, such as physical characteristics and diseases, would be more genetically determined. Among these, some would depend entirely on genetic inheritance, without the possibility of treatment, such as P2 says:

“I know there are traits that will surely generate diseases sometime in the future and not all have treatment available. This would mean that the person is marked and then it is over. But not all diseases are like that.”

The psychological characteristics, such as personality, would be more influenced by environmental factors like how one is raised and educated. According to Duden and Samerski (2007), when we consider genes “predisposed to defects” they become material, concrete, labeled with their own defect. The reluctance to relate these “material genes” to abstract things such as behavior was pointed out by P9:

“It’s interesting to see the DNA, which for me is so material, influencing attitudes.”

The definition of what is genetic is not always clear, but most people are able to provide examples of traits that “occur in the family,” without necessarily relating them to genes and DNA (Lanie et al. 2004). This personal experience that personality traits may come from the family is exemplified by P5:

“I don’t know if it is related to DNA, but I noticed, during vacation at an aunts’ house who I actually do not know very well, that they have the same habits as mine.”

In another example, a physical condition repeated in the family is immediately evaluated by P11 as “genetic.” Although P11 has argued, in another moment, the role of

the environment in the genesis of diseases, her problem was considered inevitable as it is genetic:

“I had my gallbladder removed at 22 years old. Since I was born I was told that I would remove the gallbladder, once my mother, my father, and my grandparents had theirs removed as well. It’s genetic.”

Violent behavior was considered to be predominantly influenced by the environment. But there could be individuals whose violence is innate, as stated in the expression “it is in the blood.” The aforementioned expression refers to the eugenics of the early twentieth century and still remains as a deterministic explanation for some traits of personality (Nelkin and Lindee 1995). As P17 says:

“There are people born with the intention of doing bad things, but the environment is also related. (...) But there are people who actually are born to be mean, it’s in the blood. Now, whether it’s in the DNA, I do not know.”

The sessions brought up a fear of genetic reductionism, which could be harmful in several ways. One of them is prejudice against individuals considered genetically inferior, making it difficult to obtain health insurance, employment, and even school, as it would be worthless to invest in someone less intelligent, for example. Moreover, there were discussions in the sessions about the use of traits supposedly genetic as an excuse for inappropriate behavior and for the absence of prevention against diseases. The genes would be used as an “alibi,” an excuse so people would not feel guilty for their irresponsible actions. To blame something beyond our control, combined with the difficulty to understand the concept of risk and probabilities by most people, would be facts primarily responsible for popularizing the reductionist thinking. For the participants, some people would already think in a deterministic way, ignoring the role of the environment and in the future, most would think likewise.

This view against genetic reductionism is similar to the one found in other studies that explore public opinion about genetics, suggesting that people are able to critically interpret several messages they receive (Condit 1999; Massarani and Moreira 2005). Thus, the participants in general did not endorse the concern expressed by authors related to sociology, anthropology, and philosophy that factors related to social risks will plunge in discussions about personal and family genetic risk factors (Condit 1999; Rose 2006).

### The new genetics

There was lack of knowledge about genetic tests, due to the lack of experience—the students did not know anyone that underwent them. The DNA test to determine paternity, recognition of cadavers, or forensic purposes was mentioned, but concerning diseases, nobody specifically named a test. Some

mentioned the newborn screening and prenatal exams, but the only test remembered was blood incompatibility.

The indication of predictive genetic tests divided the groups. One part considered them beneficial, as they lead to prevention. This idea is supported by studies that show there may be little increase in anxiety and behavioral changes in people with positive results in genetic tests (Delatycki et al. 2005), but that these changes are difficult and more likely in people who receive other types of guidance, in addition to test results (Marteau and Lerman 2001; Botkin et al. 2003; Weiner 2009). However, some may have an opposite behavior, once they believe in genetic determinism and feel less responsible for their own health.

The interval between the tests and the possible development of the tested disease was considered significant, with short-term predictions perceived more positively. The early treatment of the disease was also considered. The diseases that are incurable today, according to P9, those that make you “hostage,” could become treatable following the discovery of their genetic basis.

Those who disagreed with predictive genetic testing talked about psychological risks, such as over preoccupation, depression, and somatic symptoms facing an unfavorable test result. They perceived that the reaction would depend on how prepared to undergo predictive genetic testing a person would be, or on the personality of each individual, in agreement with the literature on this subject, showing that bad reactions could be related to individual levels of anxiety and depression and not necessarily to the exam itself (Green et al. 2009). Another concern of the group was that results based on probabilities are difficult to explain, especially to people with less education. This difficulty is real and occurs not only because of a lack of literacy, but also because, in health, the risk is characterized through probabilistic terms by experts, which links it to an aura of science, intangible and incontestable (Petersen and Bunton 2002).

Genetic testing without medical supervision was strongly criticized in a group, as P12 has reported seeing ads of tests that could be ordered online and mailed. In fact, as shown by Bowen et al. (2005), the advertisements for genetic tests aimed directly at the consumer have simplifications and omissions, leading to inappropriate use of tests, as the demand for them increases, but not the knowledge about it. This same group mentioned the economic interests behind the discoveries related to the diagnosis of disease, as researchers can be motivated by idealism, but only find financial support when the research is of interest to the pharmaceutical industry:

“It’s the capitalism. The higher the probability to have the disease, the more you look for medicines and techniques to prevent it, and the industry will sell more.”  
 “They found the gene for cancer. Not because it was a nice thing, but because they want to sell a new drug.

The pharmaceutical industry is investing, not the government.” (P12 and P11, respectively)

Other risks were also pointed out, such as the use of test results by employers and health insurance plans. Another risk would be that the popularization of predictive tests would lead to actions such as prenatal selection of non-pathological traits, like eye color, or even to genetic manipulation of these traits. If in the future, prenatal exams were universal, avoiding the birth of children with birth defects and prejudice against disabled people born before this time could increase, as well as prejudice against parents who refuse to undergo prenatal tests.

The feeling of responsibility with future generations emerged from the concept that sperm and egg donors should undergo genetic testing and that, when tested for some disease, the individuals will not only benefit themselves but also their descendants. Participant P2 stated that if he was a sperm donor, he would like to be tested, but did not want to know the results.

The etiology of birth defects was considered to be both genetic and environmental. Among the genetic causes, parental consanguinity was mostly mentioned, with examples of family and pets. It was considered that what is genetic cannot be changed; therefore, the prenatal diagnosis of these conditions would only be useful to start an early treatment. Although they have spoken about “avoiding” the birth of babies with genetic problems, the idea of abortion was only brought up in one group and soon disregarded:

“It’s a matter of testing, not of changing. It would be ideal, but if you cannot change, will you have an abortion? I think it would not be valid.” (P7)

The advanced maternal age, an important risk factor for malformations, was forgotten, except when they were directly asked about risk factors for Down syndrome.

The most mentioned environmental causes were: smoking, drinking, illicit drugs, and medication, as well as “bad habits” in general. Radiation was brought up by some participants, such as P6, who reported being “quite afraid of X-rays.” Although radiation in a routine X-ray exam, for example, does not increase the risk of malformations (Brent 1986), this type of fear is part of people’s imagination (Cwikel 1997).

In a Brazilian study conducted with postpartum women (Garcias and Schüler-Faccini 2004), the recognition of risk factors such as smoking, drinking, drugs, and consanguinity—all mentioned spontaneously in our groups—was associated with higher social classes, probably with more years of formal education, like our participants.

Regarding prevention, the importance of prenatal care stood out, with vague references to tests that must be done before pregnancy. Measures such as avoiding teratogens and “healthy habits” were mentioned. Also, the group questioned if prevention merely before pregnancy or parent’s bad habits along life would cause problems.

When asked about actions on preventing birth defects, none pointed out the fortification of flour with folic acid, which is mandatory in Brazil since 2002 (Vecina Neto 2002). The only participant who mentioned this substance was P18, a food engineering student, who believed it was used to prevent malnutrition. The lack of information on the role of folic acid had already been pointed out in a Brazilian study in Mezzomo et al. (2007).

Few students spontaneously remembered the vaccination campaign against rubella in 2008, whose primary target were males (Brasil, Ministério da Saúde 2009). Although most of the males involved were vaccinated, none of them remembered and some did not even understand about the need to eradicate rubella in the country. Women related rubella mostly to congenital malformations, and two of the groups mentioned it as a risk factor even before being asked about the vaccine.

When asked about the percentage of children born with birth defects, most overestimated the actual numbers with values between 10 and 40 %. When asked why the estimated values were so high, they justified with the visibility of people with birth defects in campaigns and the large number of institutions aimed at rehabilitating them. Only one group estimated the percentage between 1 and 5 %, quite close to what is found in Brazil, about 2 to 3 % of births (Castro et al. 2006). This group reached these correct estimates by recalling daily life situations, as exemplified by P1: “In a classroom, how many of them were?”

Some believe that the number of malformed children is increasing because of factors such as pollution, radiation, and poor diet, such as the consumption of transgenic food, for example. Once again, the greater visibility of disabled people was the reason, as:

“There is much talk about it now, everywhere we go we see [people with disabilities or malformations]. I do not remember seeing anyone on the street or in school as a child.” (P7)

According to the literature, the percentage of malformed births remained stable over the past decades (Horovitz et al. 2012). The perception of increased number of children with malformations expressed by the focus groups probably comes from the improvement in diagnosis and treatment of such conditions and by the increased survival of the affected ones (Herrera et al. 2001, Dastgiri et al. 2002). Moreover, the social integration of disabled people is recent, beginning in the 1970s, boosting up in the 1980s, as a result from groups that fought for rights of disabled people. In Brazil, the so-called inclusive education placing them in regular school classes began in the mid-1990s (Miranda 2003). At this time, most of the participants were already in school and saw this change in the profile of students.

## Genetic manipulation

The issue of genetic manipulation of embryos arose during the discussion on genetic testing, and the ethical issues about what should or should not be tested overlapped what should or should not be manipulated. For the participants, it seemed that to know the molecular basis of some condition, pathological or not, is the first step to change it, for example:

“If you can understand further about DNA, however slightly, it will influence the baby that is forming, something that you can do to try to change.” (P2)

There were not many considerations of technical obstacles:

“But it’s sort of impossible, right? Because the DNA molecule is huge, you will find a gene that will create ...” (P18)

Although they were really not sure on what could be done immediately, everyone assumed that at some point in the future, manipulation will be a reality and there was a lively discussion on this issue.

About what can already be manipulated today is unknown, but some “guesses” were brought up, such as:

“I read about this doctor being accused of manipulation, to choose the baby’s sex.” (P17)

“In the U.S. you can now change eye color, I’ve heard that.” (P11)

“It’s like the tests made in Asia, where all those children were born with deformities.” (P12)

In one of the groups, a participant (P2) said he believed that, currently, it is not possible to change traits, but to select those desired by the parents. In this situation, he said, “the genome of each one would be the limit” and all the fetuses would be “natural.”

The opinion of what should be allowed varied among the participants. All agreed that the manipulation to avoid serious diseases, according to P11, “the type that will put the child in a wheelchair,” should be allowed. The controversy took place concerning non-pathological traits. Most of them disagreed in changing the appearance, even if this change would give the child a greater chance to become successful in personal and professional life, as it would be using “science to the service of futility” (P9). This participant’s statement, oriented by moral standards, seems to be prevalent when it is necessary to express one’s opinion on similar issues (Meisenberg 2009).

Some have argued that setting limits would be against freedom of choice. Moreover, wealthy people could cheat possible laws, in a type of black market of genetic manipulation. All agreed that people want “perfect children,” the difference is that, for some, being perfect is the same as being healthy, for others, such as P6, “to never have problems,” yet, for others, to be perfect is to be “blond and blue-

eyed,” said P5, making it clear that he disagrees with this idea. According to P16, the pursuit of perfection is inevitable and humans always want to “change for the better (...) all religions have a perfect being, such as God. (...) And the human being searches for perfection.”

The groups also discussed the possibility of a change in mentality and habits, with manipulation of traits becoming so common as to be the rule, with no limits on what can or cannot be done. Having a child would be, for P4, as “going to the supermarket,” which for some would be something bad but for others would be good, and “whoever feels bad about, just don’t do it” (P3). But, if the society norms changed, most of them would agree to have a child genetically modified, especially concerning intelligence, so they would not stay behind. This type of change in society was exemplified by P17, regarding use of silicone implants:

“A while ago women with small breasts simply had small breasts. Today they get silicone implants. This could be done by manipulation. There is no way to control it. The tendency is for people to change their minds. Before, when someone would get silicone, I’d think, is she going to live with a plastic? In the future, genetic manipulation will be normal.”

The possible side effects of genetic modification were discussed, such as cloning of human beings done for vanity, the production of monstrosities, accidentally or intentionally, the creation of new diseases, and the use of genetic manipulation such as sports doping and changing other traits other than those intentionally modified. More abstract consequences for “perfect” human beings created by genetic engineering would be psychological problems, by the burden of being “objects of parental desire” (P12) or moral weakness, due to an alleged absence of suffering and obstacles in life, as described P17:

“Nobody wants to feel pain anywhere; they want everything in life easier. This is bad because the main reason of being a man or a woman is to be able to live and to overcome obstacles, through difficulties, through pain. (...) Everybody is already empty today, there is nothing to believe in. Do I believe in God or in Science?”

Concerning human cloning, all agreed that there are groups trying to do so and most of the participants think that this has been achieved, although not disclosed. The arguments used to justify this belief were the progress in technology, “if they clone sheep, why not humans?” (P15). Some participants also were of the opinion that governments hide some of these developments, summarized by P12:

“I think there are [clones], but nobody discloses it. I don’t really like the conspiracy theory, but we know that many governments, especially the American, hide a lot (...) In the Cold War, they achieved technical

advance (...) In 1997, when they cloned Dolly, it was to show everyone that this was possible.”

Moreover, why are there laws banning cloning, once “if it was not possible to do it, why ban it?” (P10). There was unanimity about the need to ban reproductive cloning and the possibility of giving permission to clone isolated organs for therapeutic purposes. This popularization of cloning concepts and the idea of immorality of reproductive cloning arose in 2002, from the advertising made by members of a religious group known as the Raelians, saying they had succeeded in producing the first human clone. This statement led to a strong debate on human cloning, and scientists had to expose their opinions to the public (Ingram-Waters 2009). Although cloning has been disregarded as a fraud, it seems to persist in the public’s mind.

The groups also disagreed about who should be responsible for setting the limits for manipulation or cloning. Some felt it should be professionals with technical and scientific knowledge, and others felt that it should be the government, supported by research, but only “reliable” governments. P17 mentioned “the elite,” for her, people associated to economics and finance because “it is always about economics.” The general public’s opinion could be heard, but with caution, as people may not know what they want, or may not want what is right, due to ignorance and by “not knowing how to vote” (P2), once “too much democracy can lead to ignorance” (P15). Some felt that the limits would be established by divine intervention, as “man cannot change what God has created” (P10) or by natural disasters. Those that agreed with the right to choose, and those who saw the inevitable existence of a “black market” of genetic manipulation thought that the users themselves—in this case, future parents, should choose what they would like to change, even with the possibility of potentially serious errors.

The debate and controversy about genetic manipulation and human cloning led the groups to discuss important ethical issues involving many aspects of the new genetics. The need to establish limits that would protect, ultimately, human dignity is advocated by several authors (Rose 2006) and was much discussed by the groups. According to Kerr et al. (1998), the tensions and ambiguities from the public can lead to greater democratization of new technologies, allowing different opinions to enrich the discussion to establish policies related to research, and providing services and medical care in this area, avoiding prejudice and disparities.

#### Genetics and the media

The matter was considered significant for all, for many reasons—as it is involved in daily life through diseases, to learn more about how the body works, to further know about their own bodies. Thus, news about genetics often triggers interest and is read or acknowledged by the participants.

All of them reported reading the news as it caught their attention or just out of habit. The only magazine mentioned by two groups was a popular weekly news magazine in Brazil (*Época*), by its articles on health that often report genetic-related issues. Concerning TV broadcasting, the group mentioned TV news, documentaries, and variety shows.

The Internet is an important source of information for most of them, either for direct search for topics of interest or for reading news. School, mentioned during discussion on basic concepts of genetics, was not analyzed as a source of relevant information, as, according to the participants, it teaches outdated topics.

Regarding fiction, the soap opera “The Clone”<sup>1</sup> was mentioned, as well as movies related to genetic manipulation, such as “Gattaca,” “The Experiment,” and “Deep Blue Sea.” Moreover, the group mentioned movies not only about genetics, but about natural disasters, such as “I Am Legend” or related to prediction of the future, such as “Minority Report.” Some recalled medical and criminal investigation TV shows, which show genetic diseases and the forensic use of DNA. The fictional shows are generally not used as a source of information, but lead to familiarity with medical and molecular biology terms, as exemplified by P1: “I watch TV a lot, many medical TV shows; I ended up getting the vocabulary.”

The media approach was in general considered biased, capable of distorting the words of scientists, because sometimes, as summarized by P5, “science says something and the media says another.” The explanations for news sensationalism were to make the subject more attractive, increasing profits, the fact that the general public does not understand more realistic and complex explanations and the popularity of the reductionist approach, allowing the use of genes as an excuse and giving a greater hope of healing, by simplifying the etiology of diseases.

The sociologist Niklas Luhmann pointed out this trend of the public to consider the media as manipulative and unreliable, adding that “what we know about society and its surroundings, we learn almost everything through the media. This is true not only in regard to our understanding of society and history, but also about nature” (Luhmann 2000). On the other hand, scientists increasingly depend on public acceptance to legitimize their work, leading to a change in orientation of science in relation to disclosure of results. The reaction of the press to this need and to the ever increasing interest of the public toward science was a progressive “medialization” of coverage on scientific issues, making it more extensive, diverse, and controversial (Schäfer 2009). The groups showed maturity and critical ability when facing

the different media and contents generally available. That way, such media contents were ultimately used to build their knowledge, to shape their speech, and to serve as basis to their opinions, in accordance to the published literature (Condit 1999; Massarani and Moreira 2005; Bates 2005).

### Final considerations

The participants showed interest and could actively discuss and express their opinion on the proposed topics, despite of gaps in their knowledge, reflected in the difficulties with basic concepts. They used different sources of information, including fiction, to obtain knowledge and to shape their point of view. The information gathered was discussed and used to elaborate a more critical opinion on the topics. However, some myths remain, such as human cloning and fear of radiation. Despite the restrictions concerning the “lay” media, the science was considered incontestable for all groups. These results are similar to the findings of other studies, where people showed interest in genetics, gather information from a variety of different sources, and could use a “scientific” vocabulary, although sometimes they could not fully understand many genetic concepts (Lanier et al. 2004; Bates 2005; Massarani and Moreira 2005).

The themes that raised more interest for discussion in the focus groups are still far from reality, such as cloning and genetic manipulation. This probably reflects sensationalism created by the media when presenting those topics. On the other hand, the practical and potentially useful applications of genetics, such as the prevention of birth defects and the investigation of disease, attracted less attention. In the discussion about prevention of birth defects, they knew something about things to avoid, like exposure to radiation, medicines, drugs, and alcohol. Active measures for the prevention of birth defects, on the other hand, such as the use of folic acid and rubella vaccination are little known, reinforcing the need to be better publicized. Abortion in cases of congenital malformation was not even considered as an option, possibly because Brazil is historically a Catholic/Christian country, and abortion is still considered illegal, with very few exceptions (Horovitz et al. 2012).

The groups seemed to be aware of the hazards brought by genetic reductionism and of the need for some type of regulation regarding manipulation and genetic testing. The group’s ability to broadly discuss ethical issues suggests that, if properly guided, they will be able to make informed decisions accordingly. It is necessary to develop the debate on the improvement of genetics, as some of them will affect a significant number of people. This debate should include the lay public, which has proven to be able to actively participate in decisions involving research and the use of new technologies.

<sup>1</sup> Broadcasted in Brazil in 2001 and showed again in 2011 (Globo television—the most popular TV in the country)



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