

# GIVING BODY TO THE BODY: PREDICTIVE GENETIC TESTING AND SELF-DESOMATIZATION

DARLE CUERPO AL CUERPO: PRUEBAS GENÉTICAS PREDICTIVAS Y AUTODESOMATIZACIÓN
DAR CORPO AO CORPO: TESTES GENÉTICOS PREDITIVOS E AUTODESOMATIZAÇÃO

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#### **A**BSTRACT

Genetics test in predictive medicine seems to take charge of the uniqueness of any human being. Unlike preventive medicine it moves from the theoretical assumption of the knowledge of a specific individual's genetic structure and potential fragility. However, the attention paid to the gene risks placing the living and experienced body in the shadow. Sometimes, "genetic news" can make the subject in the present act like a sick person without being so, read every event in that direction, and, ultimately, fulfill the prophecy. The article goes beyond the alleged non-exceptionalism of genetic data and discusses the symbolic value that the gene has assumed and its role in reflexivity and self-perception.

**KEYWORDS (SOURCE: DECS):** Genetic testing; predictive medicine; social identification; personal identity; self-concept; body; symbolic value; relationship; genetic counselling.

DOI: 110.5294/pebi.2021.25.2.10

### PARA CITAR ESTE ARTÍCULO / TO REFERENCE THIS ARTICLE / PARA CITAR ESTE ARTIGO

Colombetti E. Giving Body to the Body: Predictive Genetic Testing and Self-desomatization. Pers Bioet. 2021;25(2):e25210. DOI: https://doi.org/10.5294/pebi.2021.25.2.10

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APROBACIÓN POR PARES: 02/01/2022

ACEPTACIÓN: 02/01/2022

#### RESUMEN

Las pruebas genéticas en la medicina predictiva parecen encargarse de la singularidad del ser humano, a diferencia de la medicina preventiva parte del supuesto teórico del conocimiento de la estructura genética y de la fragilidad potencial de un individuo específico. Sin embargo, la atención que se presta al dato genético tiene el riesgo ensombrecer el cuerpo vívido y la experiencia en primera persona. En ocasiones, las "noticias genéticas" pueden llevar al sujeto en el presente a actuar como un enfermo sin serlo, a leer cada evento en ese sentido y, por último, a cumplir la predicción. El artículo va más allá de la supuesta no excepcionalidad de los datos genéticos y analiza el valor simbólico que ha asumido el gen y su papel en la reflexividad y la autopercepción.

Palabras clave (Fuente: DeCS): pruebas genéticas; medicina predictiva; identificación social; identidad personal; autoimagen; cuerpo; valor simbólico; relaciones; asesoramiento genético.

#### **R**ESUMO

Os testes genéticos em medicina preditiva parecem se responsabilizar pela singularidade de qualquer ser humano, enquanto a medicina preventiva se move a partir do suposto teórico do conhecimento da estrutura genética e da fragilidade potencial de um indivíduo específico. Contudo, a atenção prestada ao dado genético está arriscada a agravar o corpo vívido e a experiência em primeira pessoa. Em ocasiões, as "notícias genéticas" podem levar o sujeito no presente a atuar como um doente sem ser isso, a ler cada evento nesse sentido e, definitivamente, a cumprir o predito. Este artigo vai mais além da suposta não excepcionalidade dos dados genéticos e analisa o valor simbólico que o gene assume e seu papel na reflexividade e na autopercepção.

Palavras-chave (Fonte: Decs): Testes genéticos; medicina preditiva; identificação social; identidade pessoal; autoimagem; corpo; valor simbólico; relações; aconselhamento genético.

Giving body to the body. The expression "to give body" seems to point to an act of fulfillment, giving shape to something only sketched, or even inconsistent, to make it visible to itself and others. Giving body to the body points to the need to hand over, or hand back, the soma space and a presence, wherever the perspective of the observation risks to leave it in the shade or dissolve it in the functionality of its parts. The attention to the body and its identity is, indeed, complex: in the apparent simplicity of the fact that talking about human beings means talking about bodily beings, the question of identity affects the dual level of who and what. A dissymmetry asks to be undertaken and somehow said, not to lose what is essential. "What" answers to a first and inevitable level of the ontological question, where every individual as a human being can be found, regardless of the conditions that mark their existence, story, actions, and interactions. There is a structure common to all members of our species, which makes them recognized; delegitimizing the question and evading the answer would make every speech useless, even that on the difference between individuals. However, identity does not exhaust itself in the universal concept but shaped through unique features that we can only indicate with a proper name; not (only) a human being, not (only) a woman or a man, but Emma or Frederick. An unrepeatable identity of each that both is and it is manifested only partially in a concrete physiognomy, in features of the face, in mimic and gestural expressiveness. An identity that is also the result of a story, intertwinings of situations and free acts, responses starting from what we are, and at the same time transcends the factual datum of what we are, unpredictable answers previously and narratable afterwards. This identity includes a body that is not only part of this uniqueness (almost passive affirmation) but also participates in it. Already Thomas indicated "this

flesh, these bones" to denote the human individual  $(1)^2$ ; this and these not generally "flesh and bone."

The reason for this reflection, only apparently far from the general theme of genetic tests mentioned in the title, comes from the fact that predictive medicine seems to take charge of such uniqueness finally. It no longer works based on knowledge that affects many (as preventive medicine does) but moves from the theoretical assumption of the knowledge of a specific individual' genetic structure and potential fragility<sup>3</sup>.

However, this attention to the gene, to the basic elements of the grammar of the living, can precisely convey a look, which, once again, risks losing sight of this concrete human being who is also, but not only, their genetic profile; who is not, said otherwise, identifiable by the expression of a genetic profile nor by a risk profile deductible from the first. This is why, reflecting on predictive genetic tests, we started from the invitation to "give body to the body." The aim of these brief notes should be clarified; it is not to question the legitimacy of these tests immediately but to shed light on a prior dimension necessary for their concrete evaluation. It is a matter of reflecting on the variation of bodily knowledge and, consequently, on self-perception and understanding oneself and others.

# UNIQUENESS, INFORMATION, AND SYMBOLIC STATUS

The uniqueness of a human being (and its perception) is always given in the relationship. Of course, their identity

<sup>2</sup> For an interesting deepening of the role of this passage in the study of the human person, see (2).

<sup>3</sup> See, for example, (3).

does not consist of relationships, but it is situated in and partly modified by them. From the ontological point of view, the human being, like every other living organism, comes from another than themselves, and just being children of someone indicates a relationship so original to be originating. The very beginning of every individual existence enclosed the relationship of generating and between the generating and the generated. Our parents, who have precisely engendered us, determine many features of our being at the bodily, psychological, temperamental, and character levels. Being engendered by two specific persons and not by others makes a difference because it makes different beings: the engendered is not the result only of an interaction (relationship) between the parents but brings the same interaction inscribed in his flesh, involving, in turn, an indelible relationship with each of the two and with both in a mutual relationship. In the same way, being at the origin of a third (as to say, to engender someone) modifies one's identity, making them parents.

Relationships are also the place where awareness of one's own identity begins. The same inner dialogue that each one intertwines with himself cannot occur regardless of what happens in relationships and the news that the relationship with others conveys "about oneself" without falling into a-communicative autism. This properly human duality—constant exposure to the gaze of others and ultimately inviolable intimacy—requires a reflective process of internalization and critical mediation between what the context communicates—even of what it tells us about us—and what we know firsthand regarding ourselves, who we are and whom we want to be. To not lose oneself in a centrifugal way, it is necessary to mature awareness of oneself, a realization that gives back to the subject its centrality, ontologically unavoidable

but factually anaesthetizable. What we are saying is well known to a large part of female thought that, although with different tones and directions, has always privileged the idea of "starting from oneself" from one's own experience and self-awareness practices. Experience, however, requires thought and elaboration. How, at this point, is the knowledge of genetic data placed? Can it constitute, or at least be read in this sense, as further empowerment, an enhancement of reflexivity? Can the information about the information that pervades one's body, regardless of the awareness that one has, be a tool that gives back to the subject an intimate data that belongs to them, a hidden piece finally brought to light to understand oneself, more broadly and deeply conscious?

To answer this question, it is necessary to avoid a possible and frequent misunderstanding, which is also present in international documents. For example, in 2004 in Brussels, the task force created by the European Commission to study ethical issues related to genetic testing presented the results of their work. The picture that emerged from the broad study and the 25 final recommendations (4) revolved around the cornerstone of the alleged exceptional nature of genetic data. The fundamental question was whether this could be considered as any other biophysical data or whether, on the contrary, it kept something radically different and therefore needed different regulation and protection. At the end of a year's work, the people in the group appointed by the Commission for this purpose concluded that

the sentiment that genetic data are different from other medical information ("genetic exceptionalism") is inappropriate. Genetic information is part of the entire spectrum of all health information and does not represent a separate category as such. All medical data, including genetic data, must be afforded equally high standards of quality and confidentiality at all times (4)<sup>4</sup>.

Even issues such as predictiveness or the fact that this specific information also concerns the closest relatives are traced back to variants of medical data and managed as such. It is also stated that legislation is needed to protect individuals from possible discrimination and prevent unauthorized persons and institutions from becoming aware of this information using it as a criterion for insurance policies, loans, recruitments, or others<sup>5</sup>. The 25 recommendations mentioned above reflect all of this. However, addressing predictive genetic testing only from the technical point of view of decoding biochemical bases, possibly of cost/benefit calculation (social and individual), and privacy protection, loses sight of an important aspect: the symbolic depth of the genetic question.

Materially speaking, we can see the gene as a sequence of nitrogenous bases, but what makes these particles so unique is that, unlike all other bodily elements, they have neither mechanical nor simply biochemical function while enclosing and transmitting what may appear as the least physical of the elements: information. Any other bodily constituent results from this code whose empirical basis is found in the triplets of DNA. Here, then, with its heavy and visible materiality, the body becomes the phenomenal expression of the gene that reveals itself as the actual reality, the Kantian *noumenon* finally accessible to knowledge. Genetics is knowledge of the complex basic mechanisms that regulate the bod-

the solution to the key questions rests on a theory of language and control; the key operation is determining the rates, directions, and probabilities of flow of a quantity called information. The world is subdivided by boundaries differentially permeable to information. Information is just that kind of quantifiable element (unit, basis of unity) which allows universal translation, and so unhindered instrumental power (called effective communication) (6 p172).

Describing everything in terms of information allows a reading of the powerfully explanatory reality of many phenomena; the problem arises when we propose such a description as an exhaustive definition. If what is essential is information only, the vehicle (body) through which it is transmitted will be secondary precisely because it is functional. The uniqueness itself is lost. If, instead, it is the information that is functional to individuals and individuals-in-relation, it will be also necessary to reduce the scope of knowledge of genes and genetic information. At this moment, we are not referring to the heuristic value of understanding some dynamics: knowing that different human ethnicities have

ies biochemically. In the second half of the twentieth century, however, it progressively broke the barriers that kept it true to its empiricism, becoming symbolic horizon, hermeneutic instrument, and sense generator. Little by little, reality has ended up being a matter of transmitting information: the first level of the symbolic structure that genetics has assumed is that an increasing part of biology, in the same way as communication techniques, translates the world into a coding problem. We can describe it using the words of Donna Haraway in her famous *Cyborg Manifesto*:

<sup>4</sup> Point 3.

<sup>5</sup> On ethical issues related to databases, see also (5).

in common 99.99% of genes—and that therefore the difference of race is genetically insignificant—has value in itself or that the trisomy of gene 21 is responsible for Down syndrome or that Duchenne muscular dystrophy is linked to chromosome X. What we are talking about moves to a different level, namely the fact that reference to genetic data is not limited to being presented as such, but risks becoming an interpretative paradigm of reality and, in particular, the human being if there is no adequate reflection. We could almost designate the human being as a semiotic centralizing agent. While it has a technical meaning in the linguistic circle of geneticists, it has an entirely different semantic scope once assumed in common language. As acutely observes Samerski:

Thus in the laboratory, 'gene' refers to something arbitrary. It has no algorithmic or empirical referents—'gene' stands neither for a mathematical function, such as the 'information' in cybernetics, nor for an observable phenomenon, such as the 'chromosome' in biology.

Outside the laboratory, in contrast, 'gene' appears as the building block of life and connotes boundless possibility. And it is precisely this paradox, the absent power of reference on the one hand and the enormous connotative charge on the other that makes all this talk of 'genes' so effective (7 p201).

From the perspective of the gene, we look at the body with a gaze full of notions about information; the body stops being this flesh and these bones (which make oneself and one's interlocutor present) to be seen and perceived as a syntactic construct, a text. Particularly, predictive medicine offers not knowledge about the present but the probability of a future: it does not, therefore, deliver news about ourselves but offers a profile in which we calculate the probabilities of risk. In Mendelian pathologies, we know that the pathology will develop in the future, but not when: the future, which is not yet there, falls into the present. When instead it is only possible to speak of susceptibility, we have a statistical model, and the individual is projected into it. One's body is read as the development of a program and interpreted in the light of the risk profile; as Samerski points out in many of his studies, subjectivity is transferred from the first-person pronoun (I, me) to probabilistic reasoning. Information on a DNA mutation, once communicated to the patient/ client, gives the word "gene" an unsuspected reach by offering a self-understanding model that dissolves the first singular person into risk calculation and probabilistic predictions. "The 'gene' redefines the client as a statistical construct" (8 p98). The person is no longer what appears to be and is present now, but what could be in the future, such as the genetic profile—Noumenic truth finally brought to light projects them. Each one is reinterpreted and called to manage themselves in the light of the risk profile. It does not matter whether the percentage of risk is always and only on the population and not on the individual.

Barbara Duden spoke, in this regard, of a sort of *schizo-aisthesis*, that is, a split of the sensory perception of the self that derives from the coexistence of contradictory perceptions. A woman or a man are well and have no disease symptoms but are informed of their statistical risk of having a particular disease in the future. The perception of 'one's body, punctual and situated, is irrelevant: the genetic test makes one aware of a calculable risk in every fiber. That individual and unrepeatable body must be generically read in the light of those statistical

studies. It precisely is what Duden speaks of: "the fact that 'I' becomes the personification of probability calculation is what I call Schizo-aisthesis" (9 p132). In this representative horizon, the genetic datum is taken at a level of signification that modifies self-nomination, the understanding of oneself and the other: it is no longer Emma or Frederick, but their genetic and molecular profile. Little by little, through a slow and tiring social and cultural path, we are learning not to reduce a person to his pathology or impairment, to recognize disability as a relationship between the subject with a particular state of health and the environment. Nevertheless, all of this quickly blows up when it comes to genetics. The invisibility of the data makes it paradoxically highly real and substantiated. Its statistical significance and interaction with other environmental and relational factors are subjectively unimportant: it is there and weighs like a boulder. Thus, a first answer to the question about the role of knowledge of genetic data in the reflective process of self-knowledge is found right here, in this disturbing power of understanding one's own real identity. At this point, it is not a question of anachronistically and aprioristically rejecting knowledge and a diagnostic tool which, among other things, could also, in time, open up new possibilities for early therapeutic intervention. Instead, it is a question of reappropriating it more consciously by better evaluating both the existential appropriateness of a test, its communication and reading, and how we make culture, granting it a different symbolic power.

## **RE-SOMATIZING THE "I": A CHALLENGE**

In reflecting on the impact of communicating a predictive genetic datum on the perception of oneself, we find interesting thematic assonances with what happened to the protagonist of Sophocle's tragedy, Oedipus the King.

There is a man and a fact about himself of which he is not aware but is brought to light, a reflective movement on the truth that concerns him and belongs to him. Oedipus believes that he is morally sound, that he is right, and investigates the murder of King Laius: only by revealing and punishing the culprit will he be able to appease the wrath of the gods that caused a terrible plague in Thebes. The guilt which he believes outside of him is hidden in his own life: it was him, even though he did not know his identity, who killed the old lord of the city who, in addition, was his father. Killing him and marrying his wife realized the oracle that had weighed on his birth.

Tiresias, the soothsayer, knows, and does not want to talk. He knows the story, the acts, and the events that, having already been lived, enter into the constitution of Oedipus' identity. He knows that the revelation of the secret that he keeps will bring new misfortune to the present, perhaps worse than the plague that the city needs to be rid of. Analogously, even genetic data, permanently inscribed in the body, belong to the past, mortgage the future, and risk bringing suffering to the present: those who are healthy and have no symptoms of evil, but find themselves ill, receive a revelation that lead them to reinterpret their own identity. In Thebes, however, a symptom of evil exists because the plague rages: that is why it is necessary to find the murderer of Laius. His death occurred because Oedipus' identity had been traced before his history; actually, his history is even a priori determined by that fatal murder prediction. When others tell him what happened, Oedipus discovers who he is independent of himself. The unlucky king of Thebes punishes himself for not to seeing the evil done and thus determines his poverty and blindness in the present and for the future. The knowledge of his identity in its crudeness, hidden to him so far, also overwhelms his family<sup>6</sup>. However, unlike what happens to Oedipus, a predictive genetic diagnosis brought into light is not a fact that has already been, but something that must be. At the same time, as the initial prophecy about the newborn, made by a seer, led various characters to perform a series of acts that fulfilled it—but that would not have been performed without the communication of the prophecy—, so the "genetic news" can bring the subject in the present to act like a sick person without being so, to read in that direction every event and then, ultimately, to fulfill the prophecy<sup>7</sup>.

Like Oedipus, what appears on the horizon is a conception of the self that ends up adapting its own identity narratively to a story that has been, in some way, predictively already told. We are certainly not saying that in any case, the genetic test is not to be carried out. We are drawing attention to the fact that with its statistical profile, it risks offering a representation that expels real life, making

its probabilistic projection miss the very unprecedented of everyday life, necessary to perceive oneself in one's uniqueness. The symbolic effect of genetic emphasis carries out a transformation that is not very visible but very powerful: the body is just matter, organized from a genetic program, and the very existence risks becoming not the realization of projects starting from what we are, but the execution of this program. In this way, paradoxically, the body is *desomatized* (13), made transparent (and therefore invisible), and *depersonalized*. Giving body to the body stops being a play on words and is presented here as a demanding cultural challenge.

In such a symbolic scenario and in a context in which genetic testing is increasingly common, mainly when there is a family history of genetically transmissible or late-onset diseases, genetic counseling plays a crucial role. However, such a practice cannot fall into the preconceived circle of a simple explanation for a risk profile, but help oneself not dispossess of one's own body. The question is not straightforward; proper attention not to make the meeting between the client (not yet patient) and the experts managerial or suggestive (14) risks emptying its most human meaning. The dialogue dimension proper to counseling certainly requires special attention to the existential, ethical, and psychological complexity of what can emerge and the understanding that how data are offered, even in technical nudity, is inevitably a perspective view on the picture<sup>8</sup>. We mentioned earlier how self-understanding, always immersed in relationships, requires an exercise of reflexivity, and we wondered if genetic data could constitute a kind of enhancement of this reflection. Emphasizing the symbolic value that the question has assumed, it is now necessary to add to

The dialogue that Sophocles imagines between Jocasta and Oedipus is very intense when the former has by now understood the truth that the latter still ignores: Jocasta: "No, by the gods, if you have any care for your own life, do not pry into this. My suffering's enough." Oedipus: "Take heart. For even if my mother is revealed to be a slave, three generations slave, you'll never be exposed as lowly born" Jocasta: "Please listen to me, all the same. I beg of you, do not do this." Oedipus: "There is no way that you'll dissuade me: I have got to find these matters out for sure." Jocasta: "Tm only thinking of your good with this advice." Oedipus: "This thinking of my good has been annoying me." Jocasta: "Poor man, I only hope you never find out who you are." [Translation by Oliber Taplin, Oxford University Press, 2015].

<sup>7</sup> Particularly discussed examples are bilateral preventive mastectomy against genetic mutation BRCA-1 and BRCA-2, especially when it comes to the young population, and tests concerning neuropsychiatric or neurodegenerative diseases at late-onset. See for example (10–12).

For further information on the subject, see (15).

what we have said some notes integrating the reference to relationality.

Reflectivity implicitly encloses a reference to relationality without an explicit theme. Inner dialogue is nothing more than a soul speech with itself, a dialogue (which implies duality, but not dualism) not with an imaginary interlocutor, but of the subject with themselves. In thinking about this dialogue, in which it is possible to answer the question of one's own identity (who am I?), we must take temporality seriously, the fact that we are beings immersed in time, which is not a mere juxtaposition of instants: the human being can grasp himself in a story, a story that can be narrated.

Taking up a theory of Pierce, Margaret Archer (16) distinguishes several aspects of our selves that take part in this reflective dialogue. What we can point out as 'Me,' depositary of all that each one has become in time and that, referring to what has been, belongs to the past and is the bearer of procedures and behaviors; the 'I,' or the subject in the present moment, which is the level of the self in which the subject can adequately carry out actions. It is the 'I' that must assess, decide and, in acting, can also confirm or transform the habits of the past; then there is a dimension that belongs to the future, that is, the 'You,' whom you want to become. When we dialogue with ourselves, it is the dimension of the present (the 'I') that has the power of speech and action, but it is precisely here that the projects of the future self (the 'You') and the conditioning of the past self (the 'Me') are brought together. The 'Me,' writes Archer is always the product of choices and circumstances; during each temporal segment (that is, of the history that constitutes our life), we must re-monitor in a reflective sense the things that are most important to us (ultimate

concerns) to evaluate the costs-opportunities that we are willing to bear in their fulfillment. Her thesis is that right here, the inner conversation plays a crucial role; it is the place and the moment the 'I' renews its commitment to a specific project or abandons it by reorienting the 'You.' This discourse is not solipsistic. However, because the human being is, as we saw, structurally immersed in relationships, the inner conversation itself requires the use of the word, not necessarily expressed externally, which has matured in the relationship and refers to it. The subject of conversation with ourselves derives largely from relationships with others; even when it concerns the discursive process, we interpret ourselves and redirect our actions because of what we want to be. At every moment, our identity also consists of all the things which happened to us or which we made happen, so that the past lives in the present: our characteristics, the events that concern us, what others have done and how they have somehow involved us, the commitments made, are all elements that make up the 'I' who can, by successive approximations, redirect or reaffirm their sense. The orientation of one's action and the construction of one's identity (which includes both what we are and who we are) requires us to consider the conditioning of the past and act in the present in light of what everyone grasps as their ultimate concerns, of what is most important to them. Therefore, who we are depends much on the things we care about most, and because of which, in changing situations that do not depend on us, we orient our actions<sup>9</sup>.

<sup>9</sup> When we choose and orient our action, we always establish, at the same time, an ultimate purpose *de facto*, and that is what Archer indicates with the expression of *ultimate concerns*. It may be helpful to reread in this regard some words of a short but intense text by Masnovo: "Whoever chooses necessarily has an ultimate purpose *de facto*, whether or not this ultimate

This analysis of Archer can give critical reflection paths on genetic testing and the advice that should accompany them. In the scheme of the British thinker, we find, in fact, a constant conversation of the 'I' starting from 'Me' and in view of 'You.' Now, we can see a kind of inversion of terms because of the symbolic significance that we have already seen given to gene and genetics. If we usually must assume and confront with the 'Me,' that is with the conditioning of the 'I' of the past (reaffirming it in the present or trying to change it), by predictive genetics, a crystallized data that somehow belongs to the past (it was in us even before we knew it) moves the conditioning into the future. The 'You,' who is not yet there, assumes, in some way, not the orientating (whom we want to be), but the conditioning function (who we are), just like Oedipus' fate.

This conditioning issue, that moves from the past to the future, of the 'You' who becomes 'Me,' must then be combined with social conditioning. Here, then, is that genetic counseling, far from being merely informative and explanatory of the nudity of the data, constitutes a

purpose de facto coincides with an ultimate purpose de iure. Let me explain. I cannot choose hic et nunc, that is, at this moment, without also having hic et nunc, that is, at this moment, before my eyes, anything wanted for itself. (...) Now the thing wanted for itself, that is, not wanted for anything else, not as a means and not as a way, but as a term in which it rests, is precisely the ultimate purpose de facto. Of course, the ultimate purpose de facto colors all the other things we wanted and validates them in our eyes" (17 pp23-24). The purpose of what we want here and now, this or that, and lead the action is the ultimate purpose de facto, what we care about most, the ultimate concern. This ultimate purpose, precisely because the will institutes it, can change in time, and that is why, in the various moments of life, it is the object of reaffirmation or factual negation, requiring a reflective confrontation with oneself, our reality, and the future that opens up from one's action.

place in which society makes itself present to the subject catapulted from the situated perception of themselves to the knowledge of a statistical self (the famous Schizo-aisthesis of which Duden speaks). Somehow, the consultant also has the role of an interface between the subject and the socially constructed image of the importance of a percentage point, between the subject and the collective imagination that weighs on possible health pictures. As opposed to what is generally being stated, we can say that genetic counseling cannot be entirely neutral to be such. On the one hand, counseling before testing is needed to explain the current or missing therapeutic possibilities for those diseases whose genetic basis is to be sought. The aim is to assess, with the persons concerned, the opportunity to investigate and know such data and the existential impact on oneself and the relatives who are, directly or indirectly, involved in it.

On the other hand, it is crucial to have a meeting that, following the test results' communication, helps remain in the perception of the present and not exchange the part for the whole. To say this, of course, does not mean to legitimize any manipulative pressure on people. However, it is an invitation to become aware that the enhancement of reflexivity is not a consequence of the communication of data and possible lines of action alone. It requires the ability not to desomatize the body by transforming it into a defective communicative device, not to hypostatize a probability by letting it take the place of one's bodily self, not to convert a hypothetical future into a present capable of deterministically conditioning relationships with oneself and others that are, on the contrary, present and real. Ultimately, it is necessary to leave room also for the unpredictability of what is unique and, at the same time, to remember that, whatever happens, no one is and will ever be the anonymous declination of a pathology.

# REFERENCES

- 1. Aquinas T. Summa Theologiae, I, q. 29, a. 24.
- Pessina A. Venire al mondo. Riflessione filosofica sull'uomo come figlio e come persona. In: Cariboni C, Oliva G, Pessina A. Il mio amore fragile. Storia di Francesco. Arona, XY.it editore; 2011. p. 61-93.
- Andreozzi P, Viscogliosi G, Cipriani E, Servello A, Bechini F, Marigliano B, et al. La medicina predittiva: la medicina interna del terzo millennio. Prevent Res [Internet]. 2011 Nov 21; 08. DOI: https://doi.org/10.7362/2240-2594.058.2011
- Directorate-General for Research and Innovation (European Commission), 25 Recommendations on the ethical, legal and social implications of genetic testing. Bruxelles; 2004.
- Floridi L, Luetge C, Pagallo U, et al. Key Ethical Challenges in the European Medical Information Framework. Minds Mach. 2019;29(3):355–371. DOI: https://doi.org/10.1007/s11023-018-9467-4
- Harawai D. A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century. In: Harawai D, editor. Simians, Cyborgs and Women: The Reinvention of Nature. New York: Routledge; 1991. p. 149-181.
- Samerski S. The unleashing of genetic terminology: how genetic counselling mobilizes for risk management. New Genet Soc. 2006;25(2):197-208. DOI: https://doi.org/10.1080/14636770600855267
- 8. Samerski S, The Symbolic Fallout of Gene Talk: replacing the Person with Manageable Constructs. In Rehmann-Sutter C, Füller H, editors. Disclosure Dilemmas: Ethics of Genetic Prognosis After the 'Right to Know/ Not to Know' Debate. Farnham: Ashgate Publishing; 2009. p. 97-111.

- Duden B. L'epoca della schizo-percezione. In: Buttarelli A, Giardini F, editors. Il pensiero della differenza. Milano: Baldini Castoldi; 2008.p. 125-140.
- Eisinger F. Prophylactic mastectomy: ethical issues. Br Med Bull. 2007;81-82(1):7-19. DOI: https://doi.org/10.1093/bmb/ ldm003
- Hoge SK, Appelbaum PS. Ethics and neuropsychiatric genetics: a review of major issues. Int J Neuropsychopharmacol. 2012;15(10):1547-57. DOI: https://doi.org/10.1017/S1461145711001982
- Manrique de Lara A, Soto-Gómez L, Núñez-Acosta E, Saruwatari-Zavala G, Rentería ME. Ethical issues in susceptibility genetic testing for late-onset neurodegenerative diseases.
   Am J Med Genet B Neuropsychiatr Genet. 2019;180(8):609-621. DOI: https://doi.org/10.1002/ajmg.b.32699
- Colombetti E. Relazione e de-somatizzazione Per un approccio relazionale al tema della generazione extracorporea. Med Morale. 2012;61(2):191-208. DOI: https://doi.org/10.4081/mem.2012.140
- 14. Unesco. International Declaration of Human Genetic Data; 2003 Oct 16. Available from: http://portal.unesco.org/en/ev.php-URL\_ID=17720&URL\_DO=DO\_TOPIC&URL\_SECTION=201.html
- Sommaggio P. La consulenza genetica: un ponte tra autopoiesi ed autotrascendimento. Riv scien comunic. 2010;2(2):155-180. Available from: https://www.openstarts.units.it/handle/10077/3912
- Archer MS. Structure, Agency and the Internal Conversation. Cambridge: Cambridge University Press; 2003. DOI: https://doi.org/10.1017/CBO9781139087315
- Masnovo A. La filosofia verso la vera religione. Milano: Vita e Pensiero; 1941.