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A DUTY TO KNOW TO BE AUTONOMOUS? FOCUSING PERSONAL AUTONOMY ON THE RIGHT NOT TO KNOW GENETIC INFORMATION

YORDANIS ENRÍQUEZ CANTO*

REZUMAT. **Datoria de a şti să fii autonom? Autonomia personală concentrată pe dreptul de a nu şti despre informaţia genetică.** În cadrul dezbaterii bioetice privind accesul la informaţii genetice, provocarea noţiunii de autonomie personală este evidentă atunci când se doreşte să aibă un sens de şi când se doreşte a proteja interesul unui pacient în a nu cunoaşte. O astfel de dezbatere are loc în multe domenii legate de utilizarea de informaţii genetice, articolul nostru concentrându-se pe contextul consilierii genetice. Una dintre principalele teze din această dezbatere sugerează, mai întâi, că dreptul de a nu cunoaşte despre o anume condiţie genetică nu creşte valoarea autonomiei individuale, ci mai degrabă o degradează şi, în al doilea rând, că o necunoaştere voită a rezultatelor testelor genetice este o vină. Acest articol este un răspuns la argumentele lui Rosamond Rhodes şi Rodolfo Vázquez. Teza noastră propune o argumentare care urmează un dublu contur. Primul include un argument împotriva celor care îşi exercită dreptul lor de a nu cunoaşte, afirmând că nu se poate lua o decizie autonomă, fără să avea toate informaţiile relevante. Cel de al doilea ia în considerare decizia de a nu cunoaşte despre alte persoane, concluzionând că o persoană care alege să nu cunoască informaţia genetică este iresponsabilă sau chiar vinovată. Scopul lucrării este, în primul rând, de a sugera câteva consideraţii critice privind diada: nevoie de informaţie - autonomie, iar în al doilea rând propune o analiză a cadrului teoretic care susţine că alegerea de a nu cunoaşte rezultatele diagnosticului este o ignoranţă incriminatoare.

Cuvinte cheie: *consultanţă genetică, dreptul de a nu şti, test genetic, autonomie personală, necunoaştere genetică*

ABSTRACT. **A Duty to Know to Be Autonomous? Focusing Personal Autonomy on the Right not to Know Genetic Information.** In the bioethical debate regarding access to genetic information, the challenge to the notion of personal autonomy is evident when attempting to make sense of and to protect a patient's interest in not knowing. Such a debate takes place in many areas related to the use of genetic information, however the present work focuses on the context of

* *Prof. of Bioethics, Research Department, Faculty of Health Sciences, Universidad Católica Sedes Sapientiae, Lima, Peru; e-mail: yenriquez@ucss.edu.pe.*
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genetic counseling. One of the main theses in this debate suggests first that the right not to know genetic condition does not increase the value of individual autonomy, but rather degrades it and, second, that a desired ignorance of the results of genetic testing is a guilty one. The article is a response to the arguments of Rosamond Rhodes and Rodolfo Vázquez. The thesis proposes an argumentation that follows a double outline. The first includes an argument against those who exercise their right not to know, stating that one cannot make autonomous decisions without knowing all relevant information. The second takes into account the decision of not knowing related to other individuals, concluding that a person who chooses genetic ignorance is irresponsible or even guilty. The purpose of the paper is firstly suggesting some critical considerations regarding the dyad: need of information - autonomy, while secondly proposing an analysis of the theoretical framework that argues that the choice of not knowing the diagnostic results is an incriminating ignorance.

Keywords*: genetic counseling, right not to know, genetic testing, personal autonomy, genetic ignorance*

1. Introduction

People with genetic disorder or at high risk of transmission to their unborn children have a great need for care in a wide range of matters related to their health. The same need must be also covered in the closest relatives of these persons. It is therefore essential that genetic counseling can guarantee useful, understandable and appropriate information offered by expert personnel. In this sense, the project Eurogentest underlines that genetic counselling "is a communication process that deals with the occurrence, or risk of occurrence, of a (possibly) genetic disorder in the family. The process involves an attempt by appropriately trained person(s) to help the individual or the family."[1] An attempt to help that consider the potential impact of genetic information on patients and their close relatives. This impact can be psychological[2] or deeply existential and can modify the own image and the family relationships.

[1] EUROGENTEST. *Recommendations for genetic counseling related to genetic testing* 2007. Leuven; 2007 (27.06.2015 access to http://www.eurogentest.org/fileadmin/templates/eugt/pdf/guidelines_of_GC_final.pdf).

[2] An example of this is the strong impact of a positive diagnosis of breast cancer in families with a history of this disease. Similar influences are present in patients diagnosed with Alzheimer's and families with children with muscular dystrophy. See: CABRERA E, BLANCO I, YAGÜE C, ZABALEGUI A. *The impact of genetic counseling on knowledge and emotional responses in Spanish population with family history of breast cancer*. Patient Educ Couns. 2010; 78(3): 382-8; CHAO S, ROBERTS JS, MARTEAU TM, SILLIMAN R, CUPPLES LA, GREEN RC. *Health behavior changes after genetic risk assessment for Alzheimer disease: The REVEAL Study*. Alzheimer Dis Assoc Disord. 2008; 22(1): 94-7; READ J, KINALI M, MUNTONI F, GARRALDA ME. *Psychosocial adjustment in siblings of young people with Duchenne muscular dystrophy*. Eur J Paediatr Neurol. 2010; 14(4): 340-8.

Genetic counseling is necessary in many situations where genetic tests are used. The most common are diagnostic tests in which the test is conducted in a symptomatic individual in order to confirm or exclude genetic disease. Is needed also on predictive testing conducted in healthy subjects at high risk of developing a monogenic disorder with late onset. It is necessary, in turn, on the testing process of healthy carriers *(carrier testing)* performed in order to detect a mutation that usually have limited or little consequence in the subject, but which could have consequences in their future offspring. The same need is confirmed on prenatal test performed to identify mutations or chromosomal changes during the period of pregnancy. It is in this particular context of genetic counseling, for these different types of genetic tests, that the present discussion is framed about the right not to know the own genetic condition. In consequence are out of discussion other areas in which there is a debate about this right: research on clinical settings[3] or related to the information sought and found secondarily (incidental findings).[4]

Considering that the genetic information in this complex context can be used with dissimilar purposes, it has been subject of concern and legislative work by states and international organizations. Many of the results of this work are declarations and conventions. In particular way stand out among international treaties the *Universal Declaration on the Genome and Human Rights*[5] adopted by UNESCO in 1997, the *Convention for the protection of human rights and human dignity*[6] (Oviedo Convention) and the *International Declaration on Human*

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[3] Related to this argument see: DE WERT, G. *Cascade screening: Whose information is it anyway?* European Journal of Human Genetics. 2005; 13 (4): 397-398; KNOPPERS, BM, CHADWICK, R. *Human genetic research: emerging trends in ethics*. Nature Reviews Genetics. 2005 (6): 75-79.

[4] For this purpose see: JACKSON L, GOLDSMITH L, O'CONNOR A, SKIRTON H. *Incidental findings in genetic research and clinical diagnostic tests: a systematic review.* Am J Med Genet A. 2012; 158 (12): 3159-67; SIM, K. *Biobanks and feedback*. in CHADWICK, RUTH; LEVITT, MAIRI; SHICKLE, DARREN. (eds.) *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility.* Cambridge: Cambridge University Press; 2014: 55-70; CHRISTENHUSZ, GABRIELLE M., et al. *Ethical signposts for clinical geneticists in secondary variant and incidental finding discussions disclosure.* Medicine, Health Care and Philosophy. 2014: 1-10; BUI, TH, RAYMOND, FL, & VAN DEN VEYVER, IB (2014). *Current controversies in prenatal diagnosis 2: Should incidental findings Arising from prenatal testing to patients always be Reported?* Prenatal diagnosis. 2014; *34* (1): 12-17.

[5] UNESCO. *Universal Declaration on the Genome and Human Rights.* Paris; 1997 (03/03/2015 access to: http://unesdoc.unesco.org/images/0012/001229/122990So.pdf). For a general comment on the Declaration see: N. LENOIR *Universal Declaration on the Human Genome and Human Rights: The First Legal and Ethical Framework at the Global Level.* Columbia Human Rights Law Review. 1999; 30: 537 ff.

[6] COUNCIL OF EUROPE. *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. Strasbourg; 1997 (27.06.2015 access to: http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm).

Genetic Data[7] in 2003 and the *Additional Protocol to the Convention on Human Rights and Biomedicine*[8](Protocol) in 2008.

Of all the bioethical issues related to genetic information the problem of protecting the right to genetic privacy has been considered as one that encompasses the rest. This is due to the fact that privacy protects the individual's right to control the information that is intrinsically linked to their identity. In this context it should be considered two distinct rights which are presented autonomously: the right to know information on the results of medical tests (Article 5 of the Declaration) and the right to privacy (Article 7 of the Declaration). The right to know and its corollary the right not to know the results of genetic tests are recognized on Article 5 of the Declaration. Both reflect the natural extension of individual autonomy and are considered essential guarantors of the individual's ability to choose their own lifestyle.

The right not to know (or not to be informed) of the results of a genetic test it is recognized by all of them: the Declaration (Article 5 c), by the Convention (Article 10, n. 2) and the Protocol (Article 16, n. 3). The thesis taken into consideration in this article argues against this series of treaties and conventions that have established the validity of this right, which is equivalent to the right to know the diagnosis results.[9] This line of arguments considers the illegitimacy of exercising the right not to know genetic results and suggests the duty to know it. In this sense, the inability to use the right not to know as an extension of the principle of respect for personal autonomy arises according to a logic that give priority to a duty to know before to the individual autonomy.

Theorize that a person cannot use the right not to know the own genetic constitution, as an extension of the principle of respect for personal autonomy requires rigorous arguments. Generally, supporters of State's neutrality towards the decisions of the citizens are based on the "presumption in favor of liberty"[10]

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[7] UNESCO. *International Declaration on Human Genetic Data*. Paris 2003 (27.06.2015 access to: http://portal.unesco.org/es/ev.php-RL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html).

[8] COUNCIL OF EUROPE. *Additional Protocol to the Convention on Human Rights and Biomedicine*. Strasbourg; 2008 (27.06.2015 access to: http://conventions.coe.int/Treaty/EN/Treaties/html/203.htm).

[9] The right to information is discussed in the third chapter "Private life and right to information" of the Convention and proposes that: "Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be informed must be respected." COUNCIL OF EUROPE. *Convention for the Protection...* art. 10, paragraph 2.

[10] For Joel Feinberg the presumption in favor of liberty, requires " that whenever a legislator is faced with a choice between imposing a legal obligation to the citizens or leaving them at liberty, other things being equal, he should leave individuals free to make their own choices." FEINBERG, J. *Harm to Others. The Moral Limits of the Criminal Law.* New York: Oxford University Press; 1984: 9.

claiming that can be limited only by justifiably measures. Consequently in a democratic and liberal society, restrictive State intervention are only acceptable, if reasonably valid motives are provided and are able to be demonstrate the motivations for limiting the autonomy of the citizen.

Various problems arise regarding the right not to know, especially when it comes the possibility of not knowing the genetic condition.[11] The first group of problems is manifested on the conflict between the desire of a person to know the genetic makeup and the right not to know of another blood relative. For example, when a grandson wants to make a diagnostic testing for Huntington's Chorea[12], because his grandfather died of this disease, but his father does not want to know the diagnosis result. This is a way to present the issue that represents a clash between the desire to know (of the grandson) and the right not to know (of the father). This situation, nonetheless, would be greatly simplified with a protection policy of the diagnostic data that could help to resolve the conflict.

Another way that exemplifies a common practice to invoke the right not to know is the case of a subject who assessed not to do a diagnostic genetic test, although he knows that his sister's son is affected by Marfan syndrome.[13] It is necessary to distinguish this case from others in which the patient has diagnostic results, is informed of the outcome (negative or unfavorable) and wishes to exercise the right to privacy against the intrusion of a third party (the same group family or not).[14] In this case we cannot talk about right not to know, but privacy or right to privacy.

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[11] Note that the right not to know is put on the horizon of the diagnostic practices in general and not only related to genetic testing information.

[12] Huntington's disease is an inherited disorder caused by degeneration of neurons located in specific brain areas. The onset of the disease is most common in adults between 30 and 45 years of age, but can occur at any age, from infancy to old age. The order of appearance of the symptoms and their severity can vary greatly from patient to patient. The pattern of genetic transmission of the disease is autosomal dominant. Namely that can be transmitted from a parent to a child with a probability of 50% for each child, regardless of gender or order of filiation (the firstborn, second, etc.). The mere presence of the mutated gene (TI-15) on chromosome 4 in heterozygous individuals also involves the manifestation of the disease.

[13] Hereditary connective tissue disease. It is a disorder whose causes are little known until now. Patients are tall, have heart defects and eye damage. Such defects are transmitted by a sick individual to their offspring with a 50% probability regardless of gender. The characteristics of this transmission mode is suggested that due to the presence of a dominant gene.

[14] For this discussion, see, for example SHAW, MARGERY V. *Testing for the Huntington Gene: A Right to Know, a Right Not to Know, or a Duty to Know.* American Journal of Medical Genetics. 1987; 26: 243-246; EREZ, A ET AL. *The right to ignore genetic status of late onset genetic disease in the genomic era. Prenatal testing for Huntington disease as a paradigm*. American Journal of Medical Genetics. 2010; 152 (7): 1774-1780; TONG, R. *Ethical Concerns About genetic testing and screening*. NC Med J. 2013; 74 (6): 522-525.

The approach that will be analyzed here is the one adopted by Rodolfo Vázquez[15] In his essay "*Opacidad y Transparencia. En torno a la información genética*" (*Opacity and transparency. Around genetic information*)[16] which follows the approach of the bioethicist Rosamond Rhodes.[17] Vázquez thesis refers to the exposure of Rosamond Rhodes in her essay "*Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge*".[18] The aim of the latter is to establish "whether individuals have the moral right to continue their projects without contributing to knowledge of population genetics, without cooperating with genetic family history, without exposing genetic information upon themselves and their descendants".[19] The two essays suggest reconsidering the validity of the right not to know, using an approach that formally resembles the second mode proposed: in which an individual decides not to undergo diagnostic tests, even if he knows the potential risk of being a carrier of a gene, however, presents substantial variations. The analysis goes through some paradigmatic cases.[20] These take into account a gradual link between the parties in terms of familiarity and emotional ties:

> "The first case (Tom) has to do with Huntington's disease. The disease progresses slowly, resulting in a deterioration of the nervous system that leads to disorientation, mental disorder and lead eventually to death. Symptoms appear only after 35 years and there is a 50% chance of inheriting the disease. The fact is that if the affected population is not subjected to genetic studies, hardly will be taken data to the repetition rate necessary to ensure that those affected may develop vital projects by their own and for third parties, with any chance of success. Tom's family does not have a family history of Huntington's disease, and researchers consider very interesting to learn more about this

[15] Rodolfo Vázquez is a law professor at the Autonomous Technological Institute of Mexico.

[16] VÁZQUEZ, R. *Opacidad y Transparencia. En torno a la información genética* in BRENA SESMA INGRID. (ed.) *Panorama internacional en salud y derecho*. México DF: Universidad Nacional Autónoma de México; 2007: 341-353.

[17] Rosamond Rhodes heads the Department of Bioethics and is an associate professor of "Mount Sinai School of Medicine" in New York.

[18] RHODES, R. *Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge.* Journal of Medicine and Philosophy. 1998; 23: 10-30.

[19] RHODES, R. *Genetic Links, Family Ties...*, p. 11.

[20] In the opinion of Beauchamp in casuistry using the paradigmatic cases has the following methodological characteristics: "The casuistic method start from paradigmatic cases, the conclusions are arranged based on an ethical content, and then makes a comparison confronting features morally clear and established of the central paradigm with the peculiarities of the particular cases that need a moral decision." Cfr. BEAUCHAMP, TOM L. *principialismo*. in RUSSO GIOVANNI (ed.). *Encyclopedia di Bioethics and sessuologia*. Torino: Elledici; 2004: 1395-1402: 1398. (All translation from Spanish and Italian are mine).

> disease case. Should Tom access to research and undergo a study of his genetic material? Tom is reluctant to learn anything about himself that might cause serious concerns. However, should allow the analysis by liability to third parties?"[21]

The second case is also related to Huntington's disease but the family bond is narrower:

> "The second case (Harry), (...) is filed with the situation that Harry's father died at age 49, after three years of deterioration and suffering. The family was invited to participate in the necessary test to detect the disease. Although Harry's brother was subjected to the test and were negative, Harry refused to submit to them saying that he was not interested on knowing whether he was affected or not. Harry and Sally decide to marry. Does Harry have a moral right not to know if he has the disease?"[22]

According to Vázquez such cases would disadvantaged the right not to know the own genetic condition compared to the primary duty to prevent harm to others. Genetic ignorance seems unjustifiable to Vázquez in all cases, due to abstain from actions that could avoid damage. To know although it seems a plausible approach to prevent damage, however, to know in order to avoid harm is not determined by a direct causal link. To know, by itself, does not prevent from damage, since prevention is mediated by action. Vázquez instead on these two elements is not explicit, neither on the nature of the damage that could justify a preventive intervention of the State, nor about the moral quality of actions that constitute the means to avoid the hypothetical harm.

In sum, these are the principal elements that distinguish the proposed cases: genetic diagnostic tests has not been made, however, are available; on the other hand subsist an interested of a third party *B* to perform the test in a subject *A* (he could exercise the right not to know); thus there is a possibility that a potential subject *B* (i.e. a newborn) or *C* (i.e. the spouse) may suffer an hypothetical damage, if *A* is not subjected to the proposed test. In such cases - according to the line of arguments - the subject *A* has no right not to know, but instead has the duty to know. Thus it formulated an objection to the existence of the right not to know the results of genetic diagnosis.

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[21] It is worth noting that this example lacks relevant information that can help to give more plausibility to the proposed casuistry: if there was no history of Huntington's disease in the family of Tom, why it arises helpful to researchers to conduct the study? In this case what is the meaning of the term "investigation"? Who were the others who would benefit? These questions remain unanswered in Vázquez essay. Cfr. In VÁZQUEZ, R., *Opacidad y transparencia...,* pp. 344-345.

[22] *Ibid*., 345.

Vázquez, regarding the use of genetic testing suggest: "should be included mandatory genetic testing as part of premarital tests?, or, in order to safeguard privacy should they be considered voluntarily? I don't find reasons to justify their voluntariness if could be prevented future damage caused by genetic diseases with a high probability. The omission of information would be a reprehensible act of negligence."[23] The result of this objection would produce two consequences: first, a prospective mandatory use of genetic testing; on the other, the possibility of a moral guilt in the case that the subject refuses to know. Moreover, in circumstances in which the right not to know is exercised, there is a real risk that people will be stigmatized for their "irresponsible" decisions. This exacerbates a cultural phenomenon because the language we use predisposes us to certain value judgments against individuals and their actions.[24]

Through some statements, Vázquez argues that there is a duty to know the own genetic makeup, if there is an interest of a third party, as valid enough to be considered or whether there is a possibility of damage to a third party. In other words under these conditions, there would be required[25] to submit diagnostic genetic testing or genetic identification of carriers. His statements are not, however, a simple argument against the right to privacy when there are other stakeholders; his thesis is very different indeed. The diversity lies on the differences between the following cases: not wanting to know the result of a diagnosis done, not sharing the results of a genetic diagnosis that was already done, and the duty - proposed by Vázquez - to make the genetic diagnosis.

Concerning the argument to avoid possible damage, there is a theoretical agreement between Vázquez and the Millian line of reasoning that suggest limits on individual action. This principle proposes a criterion for determining the relationship of coercion and control between society and the individual. This criterion indicates in short that "the only purpose for which power can be rightfully exercised over any member of a civil community, against his will, is to prevent harm to others."[26] If for John S. Mill the purpose of this principle is to establish the possible reasons for mitigating a prohibition (to exercise power over a citizen against his will), to Vázquez, however, the point is to justify a duty.

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[23] *Ibid*., 347.

[24] See for example WHITE, M. *Making Responsible Decisions: An Interpretative Ethic for Genetic Decisionmaking*. Hastings Center Report. 1999; 29: 14-21.

[25] In order of this obligation proposed by Vázquez, Professor José Ignacio Solar Cayón mentions that is restrictive and renders meaningless the content of the right not to know. SOLAR CAYÒN, JI. *Saber o no saber... Derecho e información genética*. Cadernos Ibero-Americanos de Direito Sanitário. 2013; 2 (2): 802-823, p. 818

[26] MILL, JOHN S. *Saggio sulla libertà.* Milano: NET; 2002: 12.

The alleged damages, regardless of how, are difficult to identify and describe.[27] If we admit that is guilty a certain type of ignorance about one's genetic condition, assuming the possibility that it may harm others, then it can be understand the scope of an approach that seeks to legitimize the need to know one's genetic condition and emphasizes the need to make it public to third parties.

In short, the theoretical discourse in question proposes, first, that the right not to know one's genetic condition does not increase the value of individual autonomy, but degrades it and, secondly, that a desired ignorance of the results of a genetic test is guilty. This reasoning follows a double outline. The first includes an argument against those who make use of their right not to know, saying that it cannot be autonomous decisions without knowing all relevant information. The second takes into account the decision of not knowing considering other individuals, concluding that genetic ignorance is guilty or irresponsible or even incriminating.

In the first section of this paper, the purpose is to give some critical considerations to the first argument that forms the dyad need for information - autonomy, and in the second, an analysis of the theoretical framework that supports that the choice of not knowing the diagnostic results is a culpable ignorance.

2. A duty to know to be autonomous?

The argument used by Vázquez and Rhodes to support the moral duty to know the genetic information, in brief, is that would be inconsistent with individual autonomy to reject information if this is relevant for a decision. The crucial theoretical step would we the need to be autonomous, at least according to Kant's moral. Vázquez suggests that the dilemma concerning the validity of the right not to know is twofold, on the one hand, the need for individual autonomy; on the other hand, the availability[28] of such information to third

[27] In recent years, especially in the Anglo world, it has produced large literature on the subject of "harm to others." Regarding the relationship of this argument in the case of disability, I have given an answer in: ENRÌQUEZ CANTO, Y. *Informazione genetica, danno di procreazione and disabilità: aggiornamenti concettuali sull'eugenetica*. MEDIC. 2012 (2): 100-112. In order to the difficulty to identify the genetic damage and the validity of the "Non harm argument" see STRONG, CARSON. *Harming by Conceiving: A review of Misconceptions and New Analysis.* Journal of Medicine and Philosophy. 2005 (30): 491-516.

[28] The element of availability of the information resulting from genetic testing is related to a third party access to it, so that they can be aware of it and can have the means to take decisions. These decisions may be of various types: related to the possible establishment of a medical treatment, for the study of the characteristics of a disease within a family group or community, or in cases related to diseases involving disabilities or to existential decisions where the symptoms of a disease can appear years after diagnosis.

parties. The author brings together two concepts (genetic information - individual autonomy), assuming the validity of a right to know and the need to recognize the own psycho-biological constitution.[29] Thus, according to the Mexican author, it would be reasonable to accept that: *greater information and publicity would result in greater autonomy of the subject.* According to these assumptions the author assumes the right to non-interference by third parties in those activities or information that the person want to keep private. In doing so, the normative perspective of the principle of respect for privacy is adopted and therefore a right not to know. Vázquez, however, on this assumption introduces an adversarial element: "greater publicity would result in greater autonomy". In this regard it should be noted that information and publicity are not similar terms: on the contrary they are in fact very different. Restricting the use of certain information, that is, not to make it public, it is generally considered as a guarantee of autonomy. Professor Vázquez proposes this contradiction because otherwise it would not be possible to sustain the next part of his thesis, so his premise is false and misleading.

Similarly, for Vázquez would be equally reasonable also admit that *more disinformation and confidentiality put in a position of greater autonomy from third parties.* His final intuition is that these two statements cannot be applied simultaneously in some particularly difficult situations. Vázquez tries to create with this opposition a paradox that is forced. On the other hand, the hypothesis that less information is translated into a lower range of autonomy, however, need to be verify and not to be accepted in a simplistic way, especially if they are related to the results of genetic testing.

There are many situations where people prefer not to know a medical diagnosis. This practice, in which patients warn doctors in advance of their intention not to know the results of the diagnosis is not unusual, for example in the diagnostic process for diseases with a fateful and fatal course. Criticism of the right not to know, argued by Vázquez, nevertheless, should be inserted in the context of genetic counseling,[30] where the gap between the possibility of

[29] The reference to the psychological condition is motivated, according to Vazquez, on the assumption that the genetic disorder determines the psychological experience. This position is justified by the example of Huntington's disease in advanced stages of the disease symptoms of violence and dementia.

[30] For Biesecker and Peters the "Genetic counseling is a dynamic *psychoeducational* process centred on genetic information. Within a therapeutic relationship established between providers and clients, clients are helped to personalize technical and probabilistic genetic information, to promote self-determination and to enhance their ability to adapt over time. The goal is to facilitate clients' ability to use genetic information in a personally meaningful way that minimizes psychological distress and creates personal control." Cfr.: BIESECKER, B., PETERS, K. *Process studies in genetic counseling: peering into the black box.* American Journal of Medical Genetics. 2001 (106): 191-198, p. 194.

using the diagnostic technique and that provide effective treatment of the disease is unsurpassed. These are cases, most of which can be treated the symptoms but the disease cannot be eliminate. In fact, Vázquez refers to people who have not been subjected to such tests (diagnostic and screening of carriers) and this sets a great difference from cases where the patient don't want to publicize the results of the tests already taken. In this regard, nonetheless, Vázquez makes any distinctions.

Why, according to Vázquez, the right not to know degrades the value of personal autonomy? The author makes some mistakes that lead to such a claim. According to him, the right to know does not help, on the one hand, to ignore the important aspects of our psycho-biological constitution. However, this ignorance could be justified - only falsely - with not wanting to take risks or anxieties that the subject himself does not want to face.[31] This is not, in his view, a strong justification for the choice of not knowing. On the other hand, he proposes that the election of genetic ignorance without limits can lead to perverse situations on detrimental to the same individual.[32] In this senses the argumentation of Rhodes is similar about the genetic ignorance - autonomy relationship:

> "(...) when I choose to remain ignorant of relevant information, I am choosing to leave whatever happens to chance. I am following a path without autonomy. Now, if autonomy is the ground for my right to determine my own course, it cannot also be the ground for not determining my own course. If autonomy justifies my right to knowledge, it cannot also justify my refusing to be informed."[33]

Vázquez and Rhodes's thesis against the legitimacy of the right not to know proposes that ignorance contrasts autonomy, understood as the ability to choose consciously. Such a statement can be summarized with the syllogism:

Premise A: the right not know negates the possibility of being informed at the expense of the election;

Premise B: only autonomous agents can choose;

Conclusion: if I refuse to know, I deny my ability to choose, therefore to be autonomous.[34]

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[31] VÁZQUEZ, R., *Opacidad y transparencia...*, p. 342.
[32] *Ibid*., 343.
[33] RHODES R. *Genetic Links, Family Ties...*, p. 18.
[34] VAZQUEZ, R. *Opacidad y transparencia...*, p. 347.

The argument of Rhodes, as in Vázquez, ironically becomes "tyrant".[35] It doesn't work because autonomy is the condition of the choice of knowing, but not to the action of knowing by itself. Being autonomous does not depend directly on knowing. To say that one is autonomous only if that person known is not entirely true, because, in fact, we chose autonomously without knowing all the elements that affect us or are related to our choice and not for that reason we cease to be autonomous.[36] Therefore argue that in order to be autonomous we should know all the facts relevant to the election, it is equivalent to demand the impossible. If the autonomous decision-making means taking decisions and absolutely full informed, the only option that remain us would be to be similar to the Archangel described by Richard Hare.[37]

In human terms owning a holistic know is unrealistic, however, following the line of thought of Vázquez and Rhodes would be required, even in the most ordinary daily decisions a complete knowledge of philosophy, psychology, biology and legislation. When we decided to study medicine and become doctors rather than, for example, engage the study of philosophy and become philosophers we are not limiting our autonomy, choosing one over the other, but simply make an autonomous choice. The same applies to genetic information, we choose our decisions based on the knowledge of our genetic makeup or in other factors. In this sense, reject the claim that the diagnostic information from genetic testing is detrimental to personal autonomy is only a supposed truth.

Finally is necessary to make a distinction between the notion of autonomy and responsibility. The latter is not part of the concept of autonomy but is rather a result of being autonomous. Autonomy regarding responsibility is a necessary but not sufficient condition. Subsists between the two, however, a strong link as a monotonic function type: the more one is autonomous, the

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[35] About the tyranny that dominates discussions of medical ethics and modern clinical practice see: FOSTER, C. *Autonomy Should chair, not rule.* The Lancet. 2010; 375 (9712): 368-369, p. 369.

[36] Authors such as T. May and R. Spellecy argues in favor of personal autonomy to enforce the right not to know genetic information in the context of reproductive medicine. The authors indicates that the limit to autonomy in these cases is similar to the renounces in a hypothetical "true voluntary slavery." Cfr.: MAY, T., SPELLECY, R. *Autonomy, full information, and ignorance genetic in reproductive medicine. The Monist.* 2006; 89 (4): 466-481, p. 479.

[37] Hare, about an Archangel on the process of making moral decisions, proposes: "Dealing with an unforeseen situation [the Archangel] is able to identify all the properties, including the consequences of alternative actions and formulate a universal principle (though perhaps highly specific), will continue in that situation, regardless of the role he occupies. Since he has no selfish feeling and is free of other human weaknesses, act in accordance with that principle, if ordered to act." HARE, RM *Moral Thinking: Its Levels, Method and Point.* Oxford: Clarendon Press; 1981: 77-78.

more it is responsible; in fact, insofar as an individual is autonomous, the more attributable are his own actions. Rodolfo Vázquez conjecture that increased information comes greater responsibility.[38] This pair, however, is an inaccurate simplification, because being responsible is not dependent on knowledge but depends of doing or not doing that can result from knowledge. This factor is subjected, on the one hand, to the possibility (what is in my power to do) and, on the other, to the morally permissible. This is because the onus is undoubtedly related to what appears on the horizon of knowledge, but not only, dependent and is limited by the practical possibilities and by the moral limits of the actions. In other words, Vazquez's claim has to be considered rough. It cannot be said unilaterally that the possibility of being better informed makes us more responsible *tout court.* In fact it would be wrong and unrealistic, and in this sense is not acceptable as valid premise to argue.

3. Rethinking culpable ignorance

Vázquez argumentative strategy to justify an "incriminating ignorance" is based on the example of the lover that doesn't want to know:

> "Mario prefers not to know if Beatriz loves him: it would be easy to ask, but as he supposed to receive a negative answer, don't ask her about and prefers to live with the illusion of Beatriz love (...) Self-deception have a certain attraction because stimulates the illusion of being loved, which is one of the best things that can happen to a shy lover (...) But, if the self-deception refers to morally important matters, can never be an acceptable excuse (...) Self-deception is a form of unacceptable evasion of responsibility."[39]

Vázquez argues his theoretical position following a deduction:

I: the right not to know the own genetic constitution is equivalent to a right to genetic ignorance;

[38] The author, however, does not refer to the actual availability of access to diagnostic tests. It would probably be fair to note that this increased "information" opportunities derived from diagnostic techniques, also depends on the actual availability of access to them. The consequences of his line of reasoning are that those who have greater opportunities to access, have greater responsibilities than those who really cannot access to techniques for economic reasons.

[39] VÁZQUEZ, R. *Opacidad y transparencia...*, p. 346. The author follows the example proposed by Ernesto Garzón Valdés. Cfr.: GARZÓN VALDÉS, E. *Algunas reflexiones sobre la ignorancia*. Isonomía: Journal of Theory and Philosophy of Law. 1999; 11: 129-148: 133.

II: therefore, not wanting to know, in some cases, is comparable to a voluntary and desired ignorance;

III: thus a desired ignorance when it comes to damage to another person, it is guilty ignorance.

A preliminary observation about the plausibility of Vázquez argument about the "incriminating ignorance" is having as key features being searched and desired. On his line of argumentation don't want to know involves a willful ignorance and this is his first theoretical step. In the example of the lover who don't want to know if his love is reciprocated by Beatriz, this determines the choice to be put it in a state of willful ignorance. The second step is aimed at bringing out the element of guilt as follows:

> "As a mere mortal, it is true that I am not required to know the impossible or whatever is only available to the experts. A healthy modest position recognizes limits to knowledge, but in matters of everyday life we do not face regularly inevitable ignorance. In most situations, ignorance can be overcome or at least should be try to be overcome with reasonable effort, when, for example, being informed of my genetic makeup makes a significant difference in making vital decisions." [40]

The desired ignorance, according to the author, can be overcome because there would be resources to overcome it. When not making use of them and remaining in ignorance has implications, then this is a culpable ignorance. According to this argumentative line, there would be an obligation to know what you can get to know, if the means are available. While the inevitable ignorance is justified (as in the case of knowledge gaps in the progress of scientific discovery), however, it is not a desired or searched one. Moreover, according to Vázquez, in the case of deriving consequences - for example, damage to third parties - there is no valid excuses for not wanting to know. The argumentation is set out below:

Premise A: Get information of the own genetic constitution through genetic testing is technically feasible;

Premise B: I'm not obliged to know the impossible, but I am obliged to know when there are available means for knowing;

[40] VÁZQUEZ, R. *Opacidad y transparencia...*, p. 347.

Conclusion: hence there is an obligation to know the genetic constitution.

Rosamond Rhodes performs other supporting strategy to give weight and validity to her theory: not only the right of not knowing devalues individual autonomy, but rather it is irresponsible. In that sense, through an argument by analogy, it examines the case of a driver blindfolded:

> "A television commercial shows a blindfolded man test driving a car so that he can fairly assess the smoothness of its ride. That man behind the wheel might later decide that he prefers driving blindfolded. When he does not see what is in front of him he does not have to take those obstacles into account: his decision-making is simplified and he is freed from a host of troubling concerns. Even though we might sympathize with his motives, we would, nevertheless, find the prospect of his driving blindfolded totally ridiculous and morally unacceptable to such an extreme as to be not worth considering. Obviously, driving a car without being able to see where you are going puts the property and lives of others in danger. No one has the right to do that. In other words, anyone who gets behind the wheel of a car is obliged to pay careful attention to his surroundings. If he is obliged to know his situation when he is driving, he has no right to choose to be in ignorance when he drives."[41]

Rhodes's argument highlights the possibility of harm to others. If her argument is focused on the perspective of the right not to know one's genetic condition - that is analogous to driving with your eyes closed - could be summarized as follows: If subsist a desired ignorance (ID) of the genetic makeup, then there would be a damage (D) to a third party involved. We point out that this statement is also valid for the thesis of Vázquez. The level of interest and commitment on knowing, as we saw in the cases presented by Vázquez, is proportionate and directly related to the existence of family ties. The more narrower are family ties with the "concerned"[42] proportionally increase the obligations of knowing the own genetic condition.

Rhodes, to offer more convincing arguments, use an example that works as analogous hypothesis[43]: if a vehicle is driven blindfolded - that is under a desired ignorance represented by (DIª), the possibility to run over someone or

[41] RHODES, R. *Genetic Links, Family Ties...*, p. 16.

[42] In the proposals of the two authors is not clear why we must consider the interests of others or their wishes and there are no specified the foundation of the obligation to respect the interests of others.

[43] A famous analogous hypothesis is that used by C. Darwin in his theory of natural selection of species, where it is considered that the development of certain species of plants and animals is similar to the result of selective breeding.

damage her property (Dª) is almost unquestionable. The strategic role of analogy would show the DI (desired ignorance) is the cause of the damage (D) to a third party. Rhodes used this analogous hypothesis to consolidate her theory, however the DI is not an obvious cause[44] of an effect like D, unlike DIª respect to Dª. The sequence of events is represented as follows:

ID <::::::::::::::::> DIª
↓ ↓
D <::::::::::::::::> Dª

The use of an example with analogic function, in addition to a rhetorical purpose, also has an epistemological value: matching one process to another, because one of the two is better understood, or seems more familiar. I emphasize that analogy is a double-edged sword due to metaphors are poetic and thereby miss accuracy. The following deductive step: the analogy implies homologation if it is formulated in the absence of certainty, is mistaken. It would be sufficient to use the *regulae philosophandi* [45] to prevent the common risk of fictitious identification of valid reasons to explaining the phenomena. Is not enough that DI involves D or D happens, to reach the conclusion that the DI is confirmed by the presence of D, or D is caused by DI. The cause of theoretical difficulty of Rhodes is seen in the introduction of an abstract entity DIª (desired ignorance) as a causal agent of an observable phenomenon, that is the damage (D). Rhodes reasoning is persuasive, but it is obviously wrong. From this point of view, there are two possibilities: the first is that Rhodes has not demonstrated the steps leading to the identification of this damage (D). For instance, if you trample someone with your car or damage the properties of this person (Dª) this is detectable - using different types of expertise -. Even so, I don't agree that to detect D is equally clear. The second possibility is that her analog deduction is presumptuous about her premises.

By the above, the analogy used by Rhodes to reinforce its first scenario is not convincing enough to be able to assume that if in the presence of IDª thus Dª. The analysis shows that the two arguments used by Vázquez and Rhodes, in an attempt to blame the right not to know one's genetic condition, are inadequate.

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[44] Cfr.: HERSCHEL, FW. *A preliminary discourse on the study of the natural philosophy*. New York: Johnson Reprint Corp; 1966: 149 "If the analogy between the two phenomena is very close and at the same time because one of them is very obvious, it is impossible to refuse to admit the action of similar causes in the other phenomenon, though not itself as obvious".

[45] The first rule suggests that things should not be allowed more numerous than those that are true and sufficient to explain the phenomena causes.

4. Conclusions

Vázquez and Rhodes's line of arguments take it to its ultimate consequences has implications that are unacceptable:

1) Not only is impossible "not to know" the own genetic condition, when a third party is involved, but there is a duty to know. As a consequence, a condition of ignorance would be guilty. Remaining in the logic according to which a duty has a correspondent right, then the duty to know the genetic condition would correspond to the right to demand this knowledge in others. In addition, an individual who chooses not to know, would place another one in disadvantage or in a condition of damage[46] and this action would make him responsible (or imputable);

2) If there is a right to require this knowledge in others, therefore, to enforce it, this would mean that there would be also an obligation to seek genetic information, i.e., that there would be an obligation of submission to diagnostic tests if someone wants to enforce this right.

3) If these assumptions were reasonably acceptable, it would not be possible to stop to the duty to know, instead it would be necessary to go further. The obligatory element is not limited to the cognitive appropriation of the genetic condition of each individual, but would require making "reproductive" decisions in some cases, to avoid "harm" to others. The hypothesis of such a need of knowledge and the possibility of damage to a third party may be, following the Millian logic, an argument in favor of the creation of a state regulatory intervention.

With these elements, it can be said that under the terms that the authors consider and thematize the problem of third-party liability in connection with the knowledge of genetic testing information doesn't help to understand the debate, or to the clarification of the existential problem linked to genetic diseases, but instead less comprehensible. A conceptual treatment of this kind can lead to paradoxical conclusions: doing in certain circumstances of the carrier of genes that encoding the expression of a disease an alleged offender and a of the future and hypothetical newborn a potential victim of negligence, leading to an unnecessary distortion of the family and of the generative human horizon.

[46] My position on this point is developed in ENRÍQUEZ CANTO, Y. *Informazione genetica, danno di procreazione and disabilità: aggiornamenti concettuali sull'eugenetica*. MEDIC. 2012 (2): 100-112.