Comments on Human Rights Committee Draft General Comment No. 36 on article 6 of the International Covenant on Civil and Political Rights, on the right to life

Comentarios al proyecto de Observación General No. 36, sobre el artículo 6, del Pacto Internacional de Derechos Civiles y Políticos, en materia de derecho a la vida

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Abstract

In July 2017, the Human Rights Committee prepared the draft General Comment No. 36 on article 6 of the International Cove-

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nant on Civil and Political Rights, on the human right to life. The opportunity to provide comments was welcomed and a comprehensive transdisciplinary document was sent commenting with regard to this right, focused from a biological sciences, philosophical anthropology and bio-juridical perspective, according to the *corpus iuris* of human rights, presenting an ontological and deontological structure in accordance with the current scientific evidence, on the right to human life, particularly in its beginning and end, from an inclusive and objective human perspective, to be taken into account by the members of the Committee, in order to reformulate stances that violate this right.

Key words: Human rights, human embryo, human life, palliative care, human person.

Introduction

The International Covenant on Civil and Political Rights (ICCPR) emerged together with the International Covenant on Economic, Social and Cultural Rights (ICESCR), to address the lack of obligations in the Universal Declaration of Human Rights.

The Pacts were drawn up, in a first phase within the framework of the United Nations Human Rights Commission and, later, within the scope of the Third Committee of the General Assembly.

States that have ratified the ICCPR have to appoint the 18 members of the Human Rights Committee. The Committee may examine communications in which a State Party complains about the non-compliance of another State Party with respect to an obligation set forth in the Covenant. In this case, the Committee may promote investigations and propose, with the consensus of the States interested in the complaint, an *ad hoc* conciliation commission to reach an amicable solution to the matter, without prejudice to the rules and protections provided for in the Covenant.

The Optional Protocol, for its part, provides that the Committee may exercise a number of powers, which are: 1) Examine communications from citizens who assume to be victims of violations of the Protocol committed by a State Party, in order to benefit from the rights contemplated in the Covenant; 2) Make general recommendations in the field of human rights; 3) Promote the adoption of international measures so that the States Parties guarantee the effective performance of the rights set forth in the Covenant. In the scope of this last competence, the current initiative of the Committee may arrive at a re-interpretation of the content of article 6, which establishes the protection of the right to life, an initiative that is the subject to critical considerations that are established within the succeeding text.

The interpretation of a treaty or an international agreement consists of determining the exact meaning that must be attributed to the expressions used by the parties in the text, with a view to solving any contrasts that may arise in the application phase of the treaty or for that matter the agreement. The interpretation of international treaties lies in the Vienna Convention on the Law Treaties, in articles 31, 32 and 33, norms that make up the hermeneutics in this matter.

There is no doubt that the most relevant phenomenon of modern legal science, which has generated a ius-philosophical reflection at the base of the 20th century constitutional movement, has been the doctrinal and normative development of the theory of fundamental rights, a development that has favored putting the legal reality of the human person in the center, with its inviolable dignity. We have witnessed the progressive awareness of the need to structure legal systems making the human person the foundation and the end of social life, whose peaceful organization is the only objective that the law can strive for. In the 1948 Declaration, however, the question of the exact identification of the subject to which to attribute the ownership of the fundamental rights that The Declaration considers has not been clearly defined, even though in the Preamble, each «member of the human family» is thus designated and the expression «human person» is expressly used. Although in article 1 it is established that: "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience…" and in articles 2 and 3 they respectively state "person" (as subject of rights in general) and "individual" (as subject holder of the right to life), however, the limits of what is attributable to the dignity of a "person" are not clear.

The essence of the fundamental rights of the human person and among these, the primary right to life, always has comprised the fact that these cannot be attributed, nor repealed by any political power, since they are not founded on an act of human will, but rather on the very nature and dignity of man. Already in pre-Christian antiquity it was clear that democracy can only exist if the majority accepts some basic premises of the social order, among them the principles of law, that is, the inviolable human rights that find their foundation in those very principles.

Until the middle of the twentieth century, there was a worldwide extensive substantial legislative homogeneity to protect of human life, including that of the unborn child, so both in the field of Roman-Germanic law, as in that of the Common law legal systems, abortion and euthanasia have been systematically banned since they are considered a crime.

When, throughout the 20th century, the Latin American peoples conquered the independence of the Spanish dominator and constituted new States, they converged these two lines of thought in the texts of the new fundamental Charters of those peoples, arriving at the creation of a an unprecedented, universalist and properly Latin American perspective, clearly based on the philosophy of natural law of Thomistic inspiration, a school of thought that had spread to those regions thanks to the reflection and work of Bartolomé de Las Casas, whom against the violence perpetrated by some Spaniards, advocated the idea of liberation of the Indians from oppression, an intention derived from the common and natural belonging to the only human family.[1]

This was the start of the foundation to a vision of natural law completely free of any metaphysical implication and only founded on a legal tradition, of Aristotelian inspiration, which deduced the rights and natural law of human rationality; a vision that would transit onto the fundamental Charters of the newly born Latin American States, constituting the essential model in the writing of the primitive draft of The Universal Declaration, whose nucleus dispositions would have been, in this way, protected from the ideologies of both the libertarian individualism as well as from the Soviet collectivism.[2]

The integral human fulfillment, which is the good of every person and of every human community, –considered united and synchronously–, is the supreme goal of law. Such integral human fulfillment demands the respect of the primal principles of the natural law, those principles of practical reason called to direct our actions towards the primary sources of the human good; primary goods are: life, knowledge, friendship, marriage, as well as *bonum rationis*. As unproveable and self-evident as they are, these intrinsic goods are known intuitively. However, at the moment in which we know them through intuition, their directive is not yet moral, but they become something morally binding when guided by the principle that makes practical reason a good in itself, which needs to be realized, it is to be considered what we have to choose by looking in the direction offered by all the principles that concern both, the individual good, and that of the others.[3]

In this sense, we should opt for those solutions whose action appears compatible with the objective of integral human fulfillment, which is the good of every person, considered as an individual and as a community. Our "being", in fact, is always a community being, a "being-with". The merely empirical data gains a deeper meaning through a phenomenological analysis that shows that the contemplation of the self, on its own right, always involves the recognition of the presence of the other, whom is an alter ego, a "like me". This means that the empirical relationality, phenomenologically proven, is based on an ontological parity of persons, which is a parity in the realization of fundamental goods, by which no man can deny dignity and value to another, without denying himself. The potential in the enjoyment of these goods, substantiates *the ontological personal dignity* of men. However, the person has complete self-awareness only as an entity-in-relation. Such relationality is not the product neither of the personal will, nor of political imposition, but rather it is an ontological determination and therefore it is a condition of human existence.

The law, furthermore, recognizes these *co-existential* relations under the form of a synchronic and diachronic regularity and objectivity, which is a guarantee of the person's being and doing. Such objective regularity of legal relations *per se*, in their essential structure, is potentially universal. The *universality* to which law aspires has to do with what is "just", that is, appropriate to the dignity of every human being, *in primis* "living". The right to life presupposes, in fact, along with dignity, the contingency also of the effective living of the subject holder of the same right, beyond the possible threat to life itself. In this sense, the right to life is configured as a special type of right, which does not give us the power to freely dispose of our life and which, however, appears inseparable from the obligation to preserve it. Beyond the right to life, the person has its absolute dignity prevailing also when the conditions in which to exercise personally the right to life are absent.

Therefore, the fundamental right to life, violated every time an innocent is intentionally killed by another, is connected with the value of human dignity and finds in dignity its condition of existence and exercise. The attack against the right to life is rooted *in primis* in a culture that denies the essential distinction between man and animal, obeying an evolutionary and biologistic conception of human life. A second reason for rejecting the right of each human being to personal life, is to reduce man to its personal performance, absent in embryos and in other human beings who suffer from serious conditions of disability. The current position and the reduction of the person to his conscious activity, are connected with a third reason used to deny the right to life: the introduction of a distinction between human being and human person, attributing in this sense the "personal" dignity exclusively to human beings who are conscious and capable of acting as persons and excluding fetuses or people who are in a permanent state of unconsciousness. Other denials of the universality of human dignity and the right to life are based on the ignorance of the existence of the natural law and of the fundamental rights that are placed in it, accepting only as sources of law, the positive laws implemented in the state ordinances.[4]

The antidote against this mentality that denies the right to life of some human beings, is in the public and legal recognition of the personal dignity of every human being, from conception to death. As, throughout history, the abolition of discrimination between free and slaves, whites and blacks, men and women, has represented a step forward in the civil conquests of nations and states, in the same way it will be necessary to surpass discrimination between human beings born and those conceived and not yet born, by overcoming it legally, because the law is also a potent deterrent with a radical pedagogical and social function. It is also necessary to extend this discourse to people whose living conditions are so precarious that it would seem natural to indulge their death wishes. The challenge, then, is primarily cultural: as the fetus cannot be considered a mere living body without dignity, in the same way it cannot be considered as an impersonal being, a man who due to a pathology or other reasons, is in the condition of no longer being able to justify the simplest functions proper of living.

It is not possible to imagine a right that legitimizes a mentality that claims to attribute "certificates of dignity" according to the circumstances and the quality of life of the subjects. One of the main achievements of modernity has consisted precisely in the objective of limiting, by means of solemn declarations, the discretionality of political power in order to recognize the ownership of the right to life and personal dignity. The public power, then, must confine itself to recognizing the right to life, not being able to absolutely claim rights in areas that do not belong directly to it.

In the same way, the choice of euthanasia, which a national regulatory framework could accept as legitimate and practicable, does not seem admissible by the same principle of absolute unavailability of life, particularly if we refer to subjects who are in an objective condition of fragility, weakness and psychological and physical vulnerability.

Human freedom, in fact, can be understood as *potestas absoluta*, which includes the right to alienate oneself, as a proposed right of the human being, excluding the previously said self-dispositive faculty. There is a core of co-essential rights to the human person that cannot be alienated, nor violated, simply because man does not own them. Important is to highlight the difference between *inviolability and inalienability*. The first concerns the others, the second is directed towards the holder of the right, who cannot lose his right, even if it has carried out acts that go in this direction (for example, selling its organs), nor can it be forced to sacrifice or give up that ownership [5] It is about defending the dignity of the person not only against threats from others, but also against possible acts of self-harm, as in the case of choosing euthanasia.

Legal Background

International Covenant on Civil and Political Rights. Entry into force: March 23, 1976.

Preamble

The States Parties to the present Covenant,

Considering that, in accordance with **the principles proclaimed in the Charter of the United Nations**, **recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world...**, recognizing that these rights derive from the inherent dignity of the human person (...)

Considering the obligation of States under the Charter of the United Nations **to promote universal respect for, and observance of, human rights and freedoms**,

Realizing that the individual, having **duties to other individuals and to the community to which he belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the present Covenant**,

Agree upon the following articles:

(...)

Art. 6:

Every human being has the inherent right to life. This right shall be protected by law. **No one shall be arbitrarily deprived of his life.**

(...)

5. Sentence of death shall not be imposed for crimes committed by **persons below eighteen years of age and shall not be carried out on pregnant women.**

(...)

Note that this general comment replaces previous general comments No. 6 and 14:

Sixteenth session (1982), General Comment No. 6, Right to life (article 6)

1. (...) It is the **supreme law with respect to which no suspension is authorized**, even in exceptional situations that endanger the life of the nation (Article 4). (...) It is a right **that should not be interpreted in a restrictive sense.**

(...)

5. In addition, **the Committee has observed that the right to life has very often been interpreted in an excessively restrictive manner. The expression "the right to life is inherent to the human person" cannot be understood restrictively and the protection of this right requires that States adopt positive measures.** In this regard, the Committee considers that it would be appropriate for the States Parties to **take all possible measu-**

res to reduce infant mortality and increase life expectancy, in particular by taking measures to eliminate malnutrition and epidemics.

(...)

Twenty-third session (1984), General Comment No. 14, The right to life (Article 6).

1. In its General Comment No. 6 (16), adopted at its 378th meeting, held on July 27, 1982, the Human Rights Committee noted that the right to life enunciated in the first paragraph of article 6 of the Covenant International Civil and Political Rights is the **supreme right for which no suspension is allowed, even in exceptional situations. That same right to life is also enshrined in Article 3 of the Universal Declaration of Human Rights adopted by the General Assembly of the United Nations on December 10, 1948. It is fundamental for all human rights.**

(...)

As it is appreciated, comments and precisions will be made for what corresponds to point 6.1 and 5.1, since they have inaccuracies and lack of objectivity

Interpretation Regarding Human Rights Matters

a) Vienna Convention on the Law of Treaties:[10]

(...)

Interpretation of treaties.

31**. General rule of interpretation**. I. A treaty shall be interpreted **in good faith** in accordance with the **ordinary meaning to be given to the terms of the treaty** in their context and in the light of its **object and purpose.**

2. **The context for the purpose of the interpretation of a treaty shall comprise, in addition to the text, including its preamble and annexes:**

a) any agreement that refers to the treaty and has been concluded between all parties on the occasion of the conclusion of the treaty:

b) any instrument formulated by one or more parties on the occasion of the conclusion of the treaty and accepted by the others as an instrument relating to the treaty;

3. Along with the context, the following should be taken into account:

a) any subsequent agreement between the parties regarding the interpretation of the treaty or the application of its provisions:

b) any subsequent practice followed in the application of the treaty by which the agreement of the parties regarding the interpretation of the treaty is established:

c) any relevant form of international law applicable in the relations between the parties.

4. A special meaning shall be given to a term if it is established that such was the intention of the parties.

32. Complementary means of interpretation. They may resort to supplementary means of interpretation, in particular to the **preparatory work of the treaty and the circumstances of its conclusion**, to confirm the meaning resulting from the application of article 31, or to determine the meaning when the interpretation given in accordance with the article 31:

I) **leave the meaning ambiguous or obscure;**

II) **leads to a manifestly absurd or unreasonable result.**

b) American Convention on Human Rights: [11]

Article 29. Interpretation Rules

No provision of the present Convention can be interpreted to mean:

a) allow any of the States Parties, group or person, to **suppress the enjoyment and exercise of the rights and freedoms recognized in the Convention or to limit them to a greater extent than that foreseen therein;**

b) **limit the enjoyment and exercise of any right** or freedom that may be recognized in accordance with the laws of any of the States Parties or in accordance with another convention to which one of said States is a party;

c) **exclude other rights** and guarantees that **are inherent in the human personality** or that derive from the representative democratic form of government, and

d) exclude or limit the effect that may be produced by the American Declaration of the Rights and Duties of Man and other international acts of the same nature.

Article 30. Scope of Restrictions

The restrictions allowed, in accordance with this Convention, to the enjoyment and exercise of the rights and freedoms recognized in it, cannot be applied except in accordance with laws that are dictated by reasons of general interest and for the purpose for which they have been established.

c) European Convention on Human Rights:[12]

ARTICLE 53 Safeguard for existing human rights. Nothing in **this Convention shall be construed as limiting or impairing those human rights and fundamental freedoms that could be recognized under the laws of any High Contracting Party or in any other Agreement to which it is a party.**

Arguments

1. Scientific

First, life can not only be seen from the legal perspective (deontology), it is also a duty to address it from the scientific-biological (ontological) side, since we are human living beings, with our own differences with other species, derived from our essence and existence:

In this regard, it is proper to define reality as indicated by the Inter-American Court of Human Rights (hereinafter, IACHR):

"For purposes of the interpretation of Article 4.1, the definition of person is anchored to the mentions made in the treaty regarding «conception» and "human being", terms whose scope should be assessed from **scientific facts**. Of which we totally agree, since many circumstances are transformed when scientific evidence reveals reality, science establishes solid criteria without a position of consensus,as they have been established in some resolutions (case Vo. V. France,[14] case A, B and C vs. Ireland,[15] and the position taken in the case of the Artavia Murillo et al. Case (*in vitro* fertilization) vs. Costa Rica), or the belief on the basis of intellectual conceptions more or less logical, or subjective ideologies, but on facts experimentally contrasted and empirically demonstrated.[13]

This case was erroneously made by the IACHR in Artavia Murillo et al. vs. Costa Rica resolution, in which the Court interpreted, among other things, Article 4.1 of the American Convention, which establishes the right to life from conception, by which it determined:[16]

"Conception» in the sense of article 4.1 takes place from the moment in which the embryo is implanted in the uterus, which is why before this event there would be no place for the application of article 4 of the Convention".[17]

"It is not appropriate to grant the person status to the embryo";[18] and

"The embryo cannot be understood as a person for the purposes of Article 4.1 of the American Convention".[19]

However, these statements cause ambiguity and inconsistencies with current science and technology, because although it is true fertilization takes place within the body of women (intracorporeal fertilization), currently it can be performed also extracorporeally, and the embryo, as a product of some assisted human fertilization technique, is left to third parties, who do not have any regulation that limits their actions, they can intervene in an arbitrary way, such as: genetic manipulation, or perform; embryo excisions, interspecific hybrids, cloning, and other interventions possible through science and technology that can affect or destroy this new reality of the human species. In its biological essence, it is one of us in its most incipient stage, and given its human nature, nothing should prevent it from having legal recognition.

The term conception is used since immemorial times in the colloquial language and describes the moment in which the life of a human being initiates, later the term passed to the medical-scientific language. William Harvey[20] and Riesco Le-Grand[21] prior to the discovery of fertilization, refer to the beginning of pregnancy with this term.

The process of fertilization was described in detail in 1852; Nelson was the first to report seeing sperm in an oocyte, in Ascaris species.[22] In 1875 Richard Hertwig finished describing other details of the fertilization, and although before, the concept was still used, it was displaced by fertilization, which is technically more specific, so that direct references, especially the definition of conception in the medical-scientific literature of the twentieth century are rather rare.

But in the scientific articles after the discovery of fertilization, where conception is compared with fertilization, they clearly associate them. In 1876 Dr. Ernst Haeckel said: "While we must consider the sperm as a cell, as real as an egg and the process of conception as the fusion of both, we must consider the new resulting cell as an independent and new organism. The mixture of both cells is the child's germ or new organism that has been conceived." "The recognition that each human being initiates their individual existence as a simple cell is a solid basis to investigate the genesis of the human being.".[23]

In 1980, Roberto Cruz Coke defines it: "Therefore, the idea of the conception of a human being is directly and unambiguously related to the beginning of his life. The conception is an act, a moment, where a biological process called fertilization takes place. Fertilization is defined as the fertilization of an egg by means of a sperm. That is, the union of a male gamete with a female gamete".[24]

This publication written just 11 years after the American Convention on Human Rights, reflects well the thinking of the time. Likewise, it is expressed in recent publications: "This process, which has been called fertilization, represents the beginning of the life of a new human individual".[25]

Conception is a term used in science, solely in the PubMed[26] database in the heading of medical-scientific articles, more than three thousand references appear, and many of its derivative terms.

It is also enlightening to know the etymological meaning of the verb to conceive: To unite two or more entities to create a third different from the previous ones.[27] The answer is evident and shows in a literal way that conception is given at the moment of fertilization, since nothing new is created when implantation takes place.

In general, the medical-scientific literature establishes as a synonym; conception, fertilization and fertilization.[28]

If we look for the beginning of human life in embryology books, everyone agrees that the beginning of life is fertilization, as we can see in the following quotes:

- "The development of an individual begins with fertilization, a phenomenon in which the sperm of the male and the female's oocyte come together to give rise to a new organism, the zygote".[29]
- "Human pregnancy begins with the fusion of an egg and a sperm".[30]
- "Human development is a continuous process that begins when a woman's oocyte is fertilized by a male spermatozoon".[31]
- "Fertilization is the moment that marks the beginning of a new life".[32]

As it was emphasized, never, as at present, there is more certainty that the embryo is a new individual of the species to which it belongs, and for that matter it is human.

Currently embryology[33], genetics, epigenetics, proteomics and development biology irrefutably show us that from the interaction of gametes (syngamy) we are faced with a new ontological reality, a new individual of the human species[34] in development.[35] To hold otherwise is not supported from a scientific point of view and therefore is denying humanity to the human embryo, the same could apply also for a seed of a plant or a mammalian egg, which in many cases are protected by the law, from that same stage, for which it would be illogical to protect the human embryo and not recognize its right to life.

Nor can it be established that human life begins with implantation in the uterus, since extrauterine pregnancies (ovarian, tubal or peritoneal) can occur, or through *in vitro* techniques[36], –that allow for embryonic development to take place several days beyond the date on which the implantation occurs under normal conditions *in vivo*–, in which third parties intervene, where the appropriate means must be provided for its development, prior to its implantation, a fact that confirms the human embryo as a new perfectly identifiable human corporeity, not being a part of the body of the pregnant woman[37], revealing the gross scientific error of the resolution of the Inter-American Court.

Recently, diverse investigations have established with reproducible and verifiable scientific evidence, the existing communication between the mother and the embryo that has not yet been implanted; that is, immediately after fertilization during the first three days before implantation. This communication occurs through embryonic vesicles that are captured by the maternal endometrium, demonstrating that there is mother-embryo communication. This mother-embryo crosstalk is part of the independence of the human embryo, confirming that it has an identifiable individuality at a microscopic and molecular level, and therefore it is an individual different from the mother.[38] It has also been observed that the embryo, in its pre-implantation phase, modulates, through highly specific signals, the activation of genes in the uterine tubes and in the maternal endometrium (such as HOXA10),[39] showing its a capacity as a master regulator of genes, showing its capability for autonomous actions and responses that order specific instructions to the genome of the mother,[40] as well as an immunological modulation that generates tolerance of the maternal immune system to the presence of the embryo *in utero*.[42, 42]

Science requires testable theories or hypotheses at an experimental level or at some level of empirical reality. It makes the reproducibility of the experiments (method) and its results, a constant, whose findings have withstood more severe refutation tests or could not be refuted, corroborating their findings in multiple experiments. Having testable statements "Testability" (empirical hypothesis) at the level of empirical and reproducible reality.

On the other hand, we are still in a time when legal science advances with nineteenth-century standards in its analysis through expert reports and *amicus curiae*, which in many ways entails the interests of an ideology. In that sense, and following the principles of exhaustivity and evolution, it has to be corroborated with what current science already has as a solid and consolidated standard.

The American Convention is the most protectionist in regard to the right to life, it establishes its safeguards from the moment of conception and in accordance with the rules of interpretation, it must first be addressed that is understood with the term "conception" –already discussed previously– with reference from the medical and biological scientific literature.

It is important to clarify that the American Convention did not define the term conception, however, it was a subject widely debated. The delegates of Brazil and Costa Rica proposed deleting this point from the final document, however the President of the Convention, Mr. Gonzalo García Bustillos, in his capacity as representative of Venezuela, defended the issue affirming that: "regarding the right to life, from the moment of the conception of the human being, there can be no concessions; a Convention that does not consecrate this principle is unacceptable". In the end, the point was accepted by majority without modifications.[43]

The life cycle of the *nasciturus* has a definite beginning and end. And each one requires, throughout its existence, in a different way and with different intensity, the necessary nutrients and the interaction with the environment in which it develops.

It is a known fact that all the books of developmental biology –used as study references in the fields of Health Sciences around the world– establish that the beginning of human life is the formation of the zygote, so we find it in the commonly used embryology book of Moore and Persuad: "Zygote: totipotent cell of great specialization that constitutes the beginning of all human beings as unique individuals. It contains chromosomes and genes that are derived from the mother and father." Or in another mandatory reference book by Carlson: "All higher animals begin their lives from a single cell, the fertilized egg (zygote). The zygote represents the initial point in the history of life or ontogeny of the individual. In its broadest sense, ontogeny refers to the total duration of an individual's life."

Simple logic tells us that each living being is necessarily and individual of the species that gave rise to it, therefore the being that comes from a human man and woman must be a human being. The ontogenetic law also points out that in multicellular organisms the onset is unicellular and that development always goes from the simple to complex. Thus, every human being initiates in this way.

Each living being has a life of its own, with a beginning and an end; and a temporary development in which it is completed, grows, adapts to diverse circumstances and transmits life. From this perspective, the beginning of an individual's life can be defined as a constitutive process.[44]

The early embryo can be distinguished by biological markers that also indicate the fate that will follow. In addition to the molecules that interconnect the membranes specifically in the different stages, each of the cells of the early embryo has a spatial and temporal history as different cells of a single organism. It´s a growth is accompanied by differentiation, and that organic growth is the unitary vital function that makes that cellular set an organism.

The condition of the organism supposes a living being that works in an organized and integral way, so that the whole is greater than the sum of its parts.[45] Fertilization triggers a series of processes in the embryo that are characterized by their independence and physiological autonomy, among these is the expression of genes that regulate the harmonic and directed development of all embryonic development, which are absolutely not dependent of the mother.[46]

Austriaco integrates the philosophical and biological perspectives into a definition of the concept: "Philosophically, an organism can be defined as a complete living substance, with its own internal principle of movement and change, which directs it towards its natural perfection, and scientifically, as a discrete unit of living matter that itself follows a path of robust development, which in turn manifests the specific self-organization of its species".[47] Goodwin[48] has a similar conception: with fertilization and zygote formation, the life a new individual of the human species begins, with a continuous and predictable development that ends in the complete formation of the organism, according to what was said in advance, the zygote within its genetic information, is already a directed organism to develop within its characteristics of its own identity, which in the case of generating from human gametes, is consequently an organism of the human species.

This assertion is so accurate that it is already being applied in embryo selection for assisted reproduction techniques. Three parameters define which morphology corresponds to the degree of intrinsic viability of the blastocyst *in vitro*; and they refer, as it is obvious, to the organization according to the axes designed with the polarization of the zygote: a) a cavitation initiated on day 4, which originates an eccentric cavity; b) the cavity expands and aligns with the region of the internal cell mass delimited by a layer of trophoectoderm, and c) the morphology of the internal cell mass presents a single origin. On the contrary, the degree of viability decreases drastically if vacuoles are formed before the expansion and even more if degenerative foci are formed in this zone.

Even, the "definition of the human embryonic secretome has the potential to expand our knowledge of embryonic cell processes, including the complex dialogue between the development of the embryo and its maternal environment".[49]

While it is true that definitions are established on the same human reality: embryo, fetus, child, adolescent, youth, adult, etc., is only and exclusively to determine a range of development within the same individual, to establish a parameter of study, since life is a continuum, there cannot be an ontological leap from pre-human to human, we are always the same, but manifesting the conditions of each stage of development, and for such development to be the most human and coherent, the most appropriate means for health must be provided.

In this sense and following the medical principle "*primun non nocere*" (first, to do no harm), medicine has expanded its scope of care from the maternal ward; currently fetal programming and Barker's theory[50] establish that there is sufficient evidence to support the concept that: «health, which we will enjoy the rest of our lives, is determined, to a large extent, by the conditions in which we develop within the maternal cloister «. Where "Programming" is the key word to determine: health or illness, during the phase spent in the womb.[51]

There is enough evidence to consider that the programming of health for the rest of life, is done according to the conditions in which our stay in the maternal womb unfolds, this being probably as important as our genetic load, that determines our mental and physical performance for the rest of our lives.[52] Currently, as an example of the importance of this stage, an homologation of nutrients used in Petri dishes is being proposed to be established for embryonic development *in vitro*.

Additionally, in medicine, where health, personal integrity and life of all people are safeguarded, progress is made in fetal medicine, where among many diagnostic tools, the use of ultrasound allows us to see the fetus and consider it a patient.

As an example, in 1963, the first blood transfusion directly to the fetus was successfully achieved. It was the first time that it was demonstrated that the fetus[54] was susceptible to diagnosis and treatment and, therefore, with the right to be considered a patient. In 1970, Scrimgeour introduced the concept of fetoscopy in prenatal medicine.[55]

The Fetal Treatment Program at the University of California, directed by Harrison, Golbus and Filly, worked during the seventies to establish guidelines that should be considered in all prenatal procedures.[56]

In 1982, the International Fetal Medicine and Surgery Society (IFMSS)[57] was founded, a forum for surgeons, perinatologists and other health professionals, aimed at sharing work experiences, this society oversees the Journal of Fetal Diagnosis and Therapy.

In the Journal of the American Medical Association, publish the paper "The fetus as patient: Ethical issues", which suggests a list of 33 congenital diseases susceptible to treatment in the fetal stage, seven of which could be resolved with intrauterine surgery.[59]

The prestigious Williams Obstetrics Manual defines the fetus as a patient, with full rights to be treated.[60]

In summary, the fetus is defined as a patient, not in terms of viability, but as an individual susceptible to scientific observation whose diseases are susceptible to diagnosis and treatment.[61]

The advancement of science enables better care from the beginning of human life, this is updated with the studies that are now made of the biochemical elements that contain the Petri dishes, looking for nutrients that are needed by the preimplantatory embryo, for the adequate development during that specific stage of its existence.

To deny what scientific evidence reveals, on an idealistic criterion, is untruthful and voluntarist.

With the adjective voluntarist we refer to the mentality of those who, with their behavior and with their words, affirm: this is so because I say it, and I am also proud of lacking rational arguments.

With the pervious facts it is possible to recognize that the embryo and human fetus is one of our species in its most incipient state, which deserves due respect and recognition of their humanity, it is illogical that it is not even granted protected species status that other species have in their same stage of life, such as seeds, larvae or eggs, considering that the human being has a special value called human dignity.[62]

On the other hand, in no part of General Comment No. 36 the extension of the protection of human life is seen, the human life of the fetus is underestimated, as a "product" (paragraph 9)[63], objectifying human reality as if it were a thing or product, and even leaving ambiguity in the criteria, unleashing a eugenic position or impeding to continue the life of a person with a disability.

The fallacious argument of provoking eugenics to have a decent life (paragraph 2)[64], or to avoid the suffering or pain of women to reach a full-term pregnancy (paragraph 9) or to not allow people with disabilities to be born, for not having a decent life option, apart from being a psychological defense mechanism for those who adduce it, is based on a false premise. People with disabilities, *per se*, are not born unhappy, nor are they unhappy about their disability, especially if it is genetic. It is the adult psychological predisposition that pushes the sentence of unhappiness to be met. If all starts by being unhappy, even unconsciously, we will end up doing actions that will make that person feel unhappy. This fact is well established in developmental child psychology.[65] Instead, the attitude of unconditional acceptance that is love, starts doing everything to make you happy, and in this way significantly supporting the development of a strong and mature personality of affected people.

The elimination or discrimination of a person prior to implantation; as it is with Down syndrome (trisomy 21), with Turner syndrome[66] (monosomy X), or Klinefelter[67] (Trisomy XXY), where the majority of patients live a normal and productive life;[68] moreover, humanists like Nicholas James Vujicic and Hirotada Ototake, with the tetra-amelia syndrome, were born without legs and arms, and according to the ideology of perfection, they would be perfect candidates for abortion; however, and *a contrario sensu*, following the *lex artis ad hoc*, the treatments and supports necessary for its inclusion must be provided.

Justifying the death of these people in the first stage of their existence, is to grant a false right, consists in a mere exercise of the "law of the strongest", which may well be a majority of consensus of experts, democratically elected parliamentarians, or a jurisdictional decision of one or a few. It is pure discretion of those who hold power, who sanction their supposed right to trample on the weakest, who in this case lacks any possibility of defense. Authorities who cannot be the ultimate source of good and evil.

The current social model considers that the problem is not in the person with disability, but in the social factors that generate their exclusion. To the extent that the barriers that prevent people with disabilities from leading an autonomous life and having the same opportunities as other citizens disappear, disability ceases to be a factor of exclusion. In this way, disability is understood as another manifestation of human frailty that should not impede, as long as possible, a full life. Accepting abortion due to the risk of a future disability implies the regression to an anachronistic and, above all, discriminatory conception of disability.

On this criterion, in 2011, five UN agencies[69] jointly prepared a report to denounce the practice of selecting the sex of the unborn through selective abortion, present in many countries of the world. In the same year, the Committee on the Rights of Persons with Disabilities made public some considerations on the report presented by Spain on the degree of compliance with the Convention, where it reproaches Spain for how it deals with disability in the current regulation on the abortion. It says that each State is free to establish its own regulation on abortion but rejects that a reason to consider abortion as lawful is disability.[70]

In that extension of the right to life, avoiding the death of any member of the human species; currently in many countries of the world, early embryos, product of assisted human fertilization and afterwards cryopreservation, are being adopted by infertile couples to support their continuity of life and be a socially born child, respecting the nature of the human embryo.

In the United States the first donation (should we say adoption, since only things are donated) programmed for embryos by a private organization, within the Snowflakes program and promoted by the Nightlight Christian Adoption, was carried out in 1997. In Australia, it has been operating for more than two decades.[71]

In New Zealand, it was approved in 2005.[72] In Spain, it was the Marqués de Barcelona Clinic, headed by Dr. López Teijón, the first to offer the adoption of embryos,[73] to solve the problem posed by having accumulated thousands of frozen embryos at that same clinic.

In the United States, according to data provided by the Centers for Disease Control and Prevention, in 2007, 67% of the 430 fertility clinics in that country offered embryo donation.

The number of children born as a result of this practice does not seem to be very high. Nightlight stated in 2010 that there were 480 donor families with 378 adoptive families. The frozen donated embryos were around 3075. In that same year (2010), they reported that 242 children had already been born and that 19 adoptive families were currently waiting for another 24 children.[74] According to Collard, until 2008, in the United States, less than 200 embryo adoption cycles had been carried out, and until 2010, the last year in which there is reliable data from that country, less than 1,000 embryos had been donated. In England, between 1992 and 2009; 1218 children were born by embryo donation, and in 2010; 269 women opted for it.

The National Committee of Bioethics of the Italian Council of Ministers issued a document entitled "L'adozione per la nascita",[75] in which ethically values the adoption of embryos, highlighting the values of solidarity, generosity and responsibility that should characterize it.

The Report of the Ethical Committee of the American Society of Reproductive Medicine (ASRM) of 2009,[76] is favorable to the adoption of embryos to express their ethical goodness for the construction of families, which are also agreed by other Bioethics committees.[77] This same Society also stated that "the sale of embryos is ethically unacceptable by itself", but the altruistic donation may be licit.

Fernando Pascual[78] states that the adoption of embryos can be a licit alternative for those who want and cannot have children, only on the condition that the process of adopting a frozen embryo is carried out as it is done in the adoption of children without parents. If this were not the case, it would be possible to facilitate the adoption of embryos by catalog, for reasons of race, sex, etc.

These facts are omitted by the Committee, doing a regressive act, on this particular.

No cause can produce an effect superior to itself. What is clearly understood is that the embryo is already and has everything to be, it is just necessary to provide the environment suitable for its development, it has no ontological transformation of something to someone, it only has its morphological and biological transformations in conformity with its development and essence.

In this journey and how it emerges from the scientific evidence, the embryo is a new individual of the human species and updated under the principle *agere sequitur esse* (the act follows the being), it is shown that the human being is restructured in its form, but not in its essence.

It is important to remember that biology shows us that during the process of forming a human being, there is no qualitative leap, the biological body is always the same from its beginning, the only thing that changes is the degree of development. On the other hand, contemporary philosophical anthropology affirms that human beings are inseparable from their corporeity, which means that biological life cannot be separated from human life. We cannot say that we are in the presence of a body of a being of the human species, biologically speaking, but we can say that we are in the presence of a human being, a person.

Finally, it is important to point the erroneous statements of those who[79] maintain that the beginning of human life comes into existence at a certain time after fertilization, saying that:

- —Implantation is the determining act of the beginning of life, since an embryo has no chance of survival if the implantation does not happen.[80] This does not seem an acceptable argument because the implantation is an event in the time of the embryo development, which can be in a natural way or transferred by techniques of assisted reproductive technologies to get implanted. Nobody can deny that the first cell that arises from fertilization coming from the union of human gametes, corresponds to the human species.
- —For others,[81] the human individual begins to be after the 14th day, because only after these days the process of implantation is completed, and the primitive stria is formed with its nutrition and protection systems essential for the later development of the embryo, and because only after this date is it sure that no twins are produced. They seem to indicate that until earlier there would not be enough life because only primitive stria allows organs to be formed with specifically human functions. To respond to this flawed thinking, we must note that the primitive stria is part of a process of development that began with fertilization,[82] and because "the fact that an individual is going to be divided later into two other individuals, duplicating, does not prevent that before dividing is one only individual",[83] thus, there is also no reason to wait the 14th day. It would be to generalize exceptions and not consider that the twinning occurs in extraordinary cases.
- —Others claim[84] that there is no human individual until the central nervous system is configured and performs its func-

> tions. This is how the beginning of life is supposedly said depends on the functions of these organs and because the scientific criterion of human death, admitted with a general character, is brain death. These authors conclude that only human life appears when these organs function. It should be said here that the formation of the nervous system itself is a demonstration of the continuity of the human development process and that the human being is defined by what it is and not by what it can do. There is also the verifiable fact of the organic continuity to helps us understand how the human being throughout its life changes physically without ceasing to be the same individual.

Therefore, with the well-founded contribution of science, today there are no arguments to discuss the condition of human life from the zygote stage, simply because there are no genes of first, second, or third category to define life.»[85] The zygote is an actual human being in the first phase of its existence. This statement is important when assessing human life and its legal protection.

It is important to consider what Spaemann said: "The question of when human life is protectable is the second issue to be addressed." A possible answer is: It is not plausible to put a limit to say: here it begins to be protectable. In this sense, that all those who try to establish such a beginning arrive at very different results.[86] Some say that since the implantation (sentence of Artavia Murillo and others vs. Costa Rica), others say that since birth (in the case of Hoerster), others state that only from the moment the individual reaches self-consciousness (i.e., a two-year-old child would not yet have the right to life). The issue of when life begins to be protectable is raised capriciously. Let's consider what Kant says: "For practical reasons, we are presented with the idea that the human person starts from fertilization. It is not a metaphysical thesis about the immortality of the soul, which begins at that moment –it could equally be said that it begins later– but the question is the expression of ignorance. We can only add that the human person identifies with the human being himself, so that, at the moment when life begins, it begins to be protectable. Everything else is arbitrariness."

2. Human dignity

"When human beings, in the weakest and most defenseless state of their existence are; selected, abandoned, murdered or used as pure" "biological material", how can we deny that they are treated not as a "someone", but as "something", thus placing into discussion the very concept of human dignity?" [87]

The issue that concerns us, is the cornerstone between the approach to the value of the person and fundamental rights, where all legal instruments in the field are recognized and supported; that is human dignity.

"If we are aware that we are hungry, hunger really begins not with the awareness of it, but with the hunger itself that was first unconscious, and then becomes conscious hunger. Analogously, we all say: "I was conceived on such a date, and then I was born in such another one, in such epoch and day". And the children ask their mother: What happened while you were carrying me in your womb? The personal pronoun "I" refers not to a conscious self, which in the maternal cloister none of us had, but to the incipient life of the human being, who would later learn to say "I" and because other human beings are saying "you" before you can say "I" by yourself. Even if that being never learned to say «I» for disability reasons, the title of son, daughter, brother or sister in a human family belongs to him, and thus, in the family of Humanity, which constitutes a community of people. There is only one reliable criterion regarding human personality: biological belonging to the human family".[88]

Currently, the same can be said of the preimplantation embryo, as in the case of Noe Benton Markham, where sixteen months before his birth (January 16, 2007), his life had been threatened by the winds and rain of Hurricane Katrina. Trapped in a flooded hospital in New Orleans, Noah depended on the counter-clockwork of seven Illinois conservation police officers and three Louisiana State police officers, who used barges to rescue him and get him out of harm's way. Although many New Orleans residents tragically lost their lives during Hurricane Katrina the following days, the account of Noah's rescue is one of the many stories of heroism in the midst of that national disaster.[89] Noah has the honor of being one of the younger inhabitants of New Orleans who were rescued from Katrina: when the police officers entered the hospital where he was trapped, Noah was an embryo frozen in liquid nitrogen containers along with another four thousand embryos, similarly it can be said of many cryopreserved embryos up to 12 years before.

We are "someone" and not merely "something". "Human dignity is a supreme, irreducible with absolute value, proper to the personal condition. In effect, "*dignitas est de absolute dictis*", dignity corresponds to those who affirm themselves in an absolute way, that what is a principle or starting point to arise from itself, to lean on itself".[90]

The being that we are, self-reveals itself as "dignified", as non-instrumentalizable, allows our practical reason to discover a concrete categorical imperative as the primary norm for the moral life. This imperative was explicitly enunciated for the first time by Emmanuel Kant that with great insight explains the following:

"Assuming there was something whose existence in itself possesses an absolute value, something that as an end in itself could be a foundation of a possible categorical imperative, that is, of a practical law. I maintain the following: the human being and in general every rational being exists as an end in itself, not simply as a means to be used discretionally by this or that will, but both in the actions oriented towards oneself and in the directed towards other rational beings, the human being must always be considered at the same time as an end. All the objects of inclination only have a conditioned value, if the inclinations and the needs sustained in them were not given, their object would be worthless. But, as for sources of needs, the inclinations themselves are so far from holding an absolute value to be discarded by their own value, that it must rather suppose the universal desire of any rational being to be totally free of them".[91]

Let's look first at the preimplantation embryo or the neonate. Many would say they are only potential people. Namely, that a zygote or a new born may or may not become people. But this can only mean two things:

a. Either there is a quantitative difference between the embryo, the newly-born and the person. Or,
b. The difference is qualitative. If the difference is quantitative, we would find that being a person would be an (accidental) property of the zygote's or the newborn's own being. That would not say more than that *being* would have to be more than a person "*pluspersona*" (this neologism could be proposed), since we cannot give what we don't have. And if he were a person he would be more than a person, so he would have more dignity, more than dignity. *Ergo,* they would be recognizing the dignity of human life itself from its origin. If the difference were qualitative, we would be affirming a clear difference between two radically different realities. So, the problem of an embryo or a neonate becoming people would be of the same type as if we were considering, for example, the possibility that a tomato could become a vehicle or something else; of course, it would be logically impossible.

On the above, it is noteworthy that Recommendation 1046 of the Council of Europe stating that the human embryo and fetus must be treated in all circumstances with due respect for human dignity. In this regard, the Universal Declaration of Human Rights links inalienable rights with the intrinsic dignity of man, while the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights establish that human rights derive from the dignity inherent to the human person.[92]

In Spanish, inherent means –for the Royal Spanish Academy–[93] that which by its nature is so linked to something else, that it cannot be separated. And inherence is the union of inseparable things by their nature. In English it has the same meaning according to the "Oxford English Dictionary".[94] Same criteria apply with French language.[95]

In that position, and following the evolutionary principle of Human Rights, the ruling of the Court of Justice of the European Union, of October 8, 2011,[96] stresse **"it would be a serious attack against human dignity, which is recognized as present in the embryo".** More recently, on August 27, 2015, the Grand Chamber of the European Court of Human Rights issued its ruling in the Parrillo vs. Italy case (Application No. 46470/11), which after reviewing its previous pronouncements, recalled that the human embryo cannot be reduced to a possession.

"Recapitulating that the human embryo is a necessary or *sine qua non* condition for the life of an adult human individual with an inherent dignity."

However, Michael Kloepfer tells us: "If in reality the question of a constitutional good at the highest level makes sense, then this is the life and not the dignity of man".[97] However, as it has been described up to now, and since it is inherent, they are consubstantially intertwined.

Therefore, the specific theme of human rights will be based on the values established in a specific historical community and the ends that it seeks to achieve, provided that the very essence of the dignity of the human person is respected as an inescapable principle, as an end on itself, otherwise we could not speak of the human being but of any other thing, even when it is just and useful.[98] On this point, what is stated as ontological dignity is reaffirmed, likewise it coincides with Gomez Maximo, pointing out “With this I wish to state that every human person has rights because they are, and they must be recognized and guaranteed by the State without any social, economic, legal, political, ideological, cultural or sexual discrimination. But, at the same time, I want to emphasize that these rights are fundamental, that is, that they are linked to the idea of dignity of the human person”.[99]

On what has been explained, it is intuited that there is an objective dignity, this is the point of departure; that is, the inherent dignity of the human person. That is why it is about inviolable rights.

With discrimination on qualitative or quantitative issues, such as capacity, autonomy, feeling, conscience, it is possible to establish criteria that discriminate against people, there are plenty of historical and recent examples to illustrate how adult and capable human beings have been denied all kinds of rights and even not being considered human beings. Slaves, Jews, women, those belonging to a certain religion or race, children, etc., have been denied their dignity, and currently embryos, fetuses, people who have a severe disabilities or are in a so-called vegetative state, for different reasons, being considered as things, disqualifying them as rights holders. The philosopher R. Spaeman reflects on this by saying: “Someone will never be something”.[100]

3. Legal assessment

The explicit recognition of a human right, and especially that of life, is the most noble activity that a State can carry out, because it grants spheres of protection to all people and limits public powers.

The indispensable presupposition of every right is life; it is the ontological basis and condition of all other rights. It turns out that the law in general and human rights in particular, involve the normative integration of human relations within the social context, and by virtue of its fair content, involves integrating the three aspects or elements that complement each other in the legal experience, this is, the normative aspect (the Law as a norm), the factual aspect (the Law as a social fact) and the axiological aspect (the Law as justice). In this case, creating norms without the end of justice, being irrational and justifying actions, without a sense of a life according to human nature and its end, would be like going back to the stone age where the law of the strongest governed, having to consider four essential axes in all legal reflection: the inalienable right to life, since it depends on the exercise of other rights, the equality of all human beings in dignity, their personal condition, and adequate biological development according to its stage of existence, as well as its autonomy to reflect and decide freely. Everything that violates, limits, or cancels any of these great pillars must be avoided or effectively counteracted.

In this context and following the argumentative and substantial line of the right to life, we can cite, among others, the following instruments that form the *corpus iuris* of human rights in accordance with the Vienna Convention on the Rights of Treaties of 1969, where it is noteworthy taking into account that the legal value of these instruments and their meaning cannot be inferred only from the letter of the law, but also from the interpretation that the *ad hoc* tribunals make of it and from the useful effect that they enjoy, in this way, this right is contextualized, and guidelines and obligations are set for the States Parties to respect, promote, and protect these rights, such as:

Universal Declaration of Human Rights

Article 3 “Every individual has the right to life, liberty and the security of his person.”

International Covenant on Civil and Political Rights (ICCP)

Article 6

The right to life is inherent to the human person. This right shall be protected by law. No one can be deprived of life arbitrary.

The European Convention for the protection of human rights and fundamental freedoms.

The right of every person to life ... (Article 2).

Convention of the European Union.

Everyone has the right to life (Article 2-1).

American Declaration of the Rights and Duties of Man

Article I. ... Every human being has the right to life, liberty and the security of his person.

American Convention on Human Rights

Article 1 For the purposes of this Convention, person is every human being.

Article 4. Right to life

1. Everyone has the right to have their life respected. This right will be protected by law and, in general, from the moment of conception.

No one can be deprived of life arbitrarily.

Regarding Article 4.1 of the American Convention, the ontological and scientific errors of the Inter-American Court, in the Artavia case, have already been laid down, which have already been overcome by the Parrillo and Oliver Brüstle cases, indicated in advance, where the evolutionary and expansive principle of human rights is updated.

It is noteworthy that even the constant and uniform jurisprudence of the Inter-American Court in this regard has been expressed in more than twelve cases.[101] In the year 2012 it has been repeated twice,[102] specifically, in two cases it has estimated the unborn as "children"[103] and "baby".[104]

Regarding the best interests of children and to clarify their defense and recognition, the IACHR expansively establishes the content and scope of human rights[105] and the obligations contained in the American Convention on Human Rights (ACHR), in the light of other legal norms; to exclude any interpretation that leads to augmenting the limitations on human rights allowed in the

ACHR,[106] and to provide effective inter-American procedural and institutional mechanisms for the protection of human rights,[107] on this particular UNESCO makes the **Declaration Of Monaco: Reflections On Bioethics And The Rights Of The Child**,[108] where in its Annex II, it establishes:

> "I. The origins of the child:
>
> — Every child is a unique and new being.
>
> — **Respect for the dignity of the embryo constituted *in vitro*** should be ensured...
>
> When genetic and fetal medicine data are used, the principle of non-discrimination must be respected and the reduction or elimination of human diversity or the hazards inherent in life must not be aimed at."

Establishing an expansion of childhood rights from the embryonic stage (*in vitro*).

It is important to highlight that assisted fertilization in humans began to have effects sometime after the Universal Declaration, Covenant of Civil and Political Rights, the Covenant of Economic, Social and Cultural Rights, as well as the American and European Convention, this can be deducted with "the first birth of a baby product of In Vitro Fertilization (IVF) that occurred in England in 1978" and "in Latin America, the birth of the first baby product of in vitro fertilization and embryo transfer was reported in 1984 in Argentina",[109] so that "before the IVF, the possibility of performing fertilizations outside the body of the woman was not scientifically contemplated".

On the other hand and more currently within the context of human rights instruments and in accordance with the precautory principle,[110] which is cited in the draft (paragraph 65) and where only in a limited way applies in the subject of environment; must also be pronounce for human life and health, as in the statement of Asilomar and more recently the conference Synthetic Biology 2.0, at Berkeley, California, referring to the "broad vote of the community" on the resolutions on biosecurity, which will be implemented on January 1, 2007,[111] likewise, the following International Human Rights Instruments may be cited:

Universal Declaration on the Human Genome and Human Rights

Article 1

The human genome is the basis of the fundamental unity of all the members of the human family and of the recognition of their intrinsic dignity and diversity. In a symbolic sense, the human genome is the heritage of humanity.

Article 2

a) Each individual has the right to respect for their dignity and rights, whatever their genetic characteristics.

b) This dignity requires individuals not be reduced to their genetic characteristics and that the unique character of each and its diversity be respected.

Article 11

Practices that are contrary to human dignity, such as cloning for the purpose of reproduction of human beings, should not be allowed. States and relevant international organizations are invited to cooperate to identify these practices and to take appropriate action at the national or international level to ensure that the principles set forth in this Declaration are respected.

Universal Declaration on Bioethics and Human Rights

Considering that UNESCO has a role to play in the definition of universal principles based on common ethical values that guide scientific advances, technological development and social transformation, in order to identify the challenges that arise in the field of science and technology, taking into account the responsibility of current generations for generations to come, and that issues in bioethics, which necessarily have an international dimension, should be treated as a whole, based on the principles already established in the Universal Declaration on the Genome Human and Human Rights and the International Declaration on Human Genetic Data, and taking into account not only the current scientific context, but also its future evolution.

Bearing in mind also that the identity of a person includes biological, psychological, social, cultural and spiritual dimensions.

Whereas it is desirable to develop new approaches to social responsibility to ensure that the progress of science and technology contributes to justice and equity and serves the interest of humanity,

General dispositions

(...)

Article 2. Objectives

The objectives of this Declaration are:

a) provide a universal framework of principles and procedures to guide states in the formulation of legislation, policies or other instruments in the field of bioethics;

b) guide the actions of individuals, groups, communities, institutions and companies, public and private;

c) promote respect for human dignity and protect human rights, ensuring respect for the lives of human beings and fundamental freedoms, in accordance with international law relating to human rights;

(...)

g) safeguard and promote the interests of present and future generations;

Principles

(...)

Article 8. Respect for human vulnerability and personal integrity

When applying and promoting scientific knowledge, medical practice and related technologies, human vulnerability should be taken into account. Particularly vulnerable individuals and groups should be protected, and the personal integrity of these individuals should be respected.

Article 16. Protection of future generations

The impact of life sciences on future generations, in particular on their genetic constitution, should be duly taken into account.

Regarding the best interests of children, the American Convention in its article 19. Rights of the Child, establishes: Every child has the right to protection measures that his condition as a minor requires from his family, from society and of the state. The Court also points out that girls and boys have the rights that correspond to all human beings –minors and adults– and also have special rights derived from their condition, to which correspond to specific duties of the family, society and the state.[112]

General Comment 5, General measures of implementation of the Convention on the Rights of the Child; points out the need for a perspective based on the rights of the child to ensure the application of the Convention, based on the General principles identified by this body: the best interests of the child, non-discrimination, the right to life, survival and development.

On the other hand, highlights the omission of the Committee in the pronouncement of art. 6.5 of the Covenant, which states: "The death penalty shall not be imposed for crimes committed by persons under 18 years of age, nor shall it be applied to pregnant women," which is supported under the International Covenant on Economic, Social and Cultural Rights (ICESCR) in its article 10: "Special protection must be granted to mothers during a reasonable period of time before and after childbirth".

In this international instrument, special protection is given to the mother due to her pregnancy status, in order to protect the *nasciturus* and the conformation of the family in the best possible way, which is confirmed by the U.N. Doc. E / C.12 / 2000/4,[113] on the application of said Covenant, General Comment 14, The right to the enjoyment of the highest possible level of health (article 12 of the Covenant), which in the following establishes:

"II. **Obligations of the Participating States...** Basic Obligations... 44. The Committee also confirms that the following priority obligations include the following: a) Ensure maternal (prenatal and postnatal) and child health care; (...) "

On the other hand, on the instruments for the protection of children, the following can be observed:

Declaration of the rights of the child

Recognizing that the child is a human being who, due to his condition, even needs due legal protection, both before and after birth, of special protection and care, and of the express recognition of his rights, the Member States of the UN wanted to express the Rights of the Child in a Special Dedicated Declaration, expressly and exclusively to children, as the most important group of human beings among the men and women of the world, urging parents, men and women individually and private organizations, local authorities, and national governments to recognize these rights and fight for their observance with legislative measures adopted progressively, proclaimed the Declaration of the Rights of the Child, which protects the human life of children thus:

(...) Considering that the child, due to his lack of physical and mental maturity, needs special protection and care, including due legal protection, both before and after birth,

(...)

Children's rights convention

Preamble

(...) Bearing in mind that, as indicated in the Declaration of the Rights of the Child, "the child, due to his lack of physical and mental maturity, needs special protection and care, including due legal protection, both before and after birth."

(...)

Article 1

For the purposes of this Convention, a child is understood to be any human being under eighteen years of age, (...).

Article 6

1. The States Parties recognize that every child has the **intrinsic right to life**.
2. The States Parties guarantee the survival and development of the child as far as possible.

   For its part, the European Convention for the protection of human rights and fundamental freedoms in its article 2: "The right of every person to life ...".

In summary, it can be known from the international instruments referred to that:

1. The right to life is recognized as a fundamental right of every human person;
2. It is consubstantial or inherent to every human person;
3. It can be taken as analogous: person, individual and human being;
4. In the case of children, the legal recognition is established verbatim from before birth, influencing any conflict of rights, their superior interest prevails;
5. The American Convention is the only legal instrument that extends the spectrum of protection from conception, and
6. **The arbitrary deprivation of life is prohibited.**[114]

It should be noted that human rights treaties are complementary to each other. Therefore, the reading must be unitary, which allows to reach the interpretation of each right recognized from different perspectives and with different degrees of approach, even within a global system. Otherwise we would be admitting the possibility of contradictions between the same treaties, or the disparate effect of them on the rights and constitutional guarantees that come to perfect or complement.

As complementary to each other, treaties are perfected among themselves, in the sense of the fullest and most perfect recognition of the right in question in a given circumstance.

"The rule of the complementarity of treaties with each other and with the constitutional text is of special importance".[115]

It is noteworthy that without a doubt the right to life occupies a special place in the list of the fundamental rights of the human person. Even when the doctrine affirms that all human rights have equal value,[116] when examining specific cases of violations of this right, the competent international bodies do not hesitate to highlight the specific nature of the right to life.

In its General Comment on article 6 of the International Covenant on Civil and Political Rights, the Human Rights Committee qualified it as:

"The supreme right for which no suspension is authorized, even in situations that endanger the life of the nation".[117]

Since then, the Committee has reiterated the phrase «The right to life is the most essential of these rights».[118] It is also indicated in the project.

For its part, the Inter-American Court of Human Rights (IACHR), on a recurring basis, states in its rulings related to this right, the parameters of protection that must be adopted by the States Parties to make it effective:

"This Court has indicated that the right to life plays a fundamental role in the American Convention, as it is the essential corollary for the realization of other rights. The States have the obligation to guarantee the creation of the conditions that are required so that violations of this inalienable right do not occur and, in particular, the duty to prevent their agents from violating it. The fulfillment of the obligations imposed by Article 4 of the American Convention, related to Article 1.1 thereof, not only presupposes that no person is deprived of his life arbitrarily (negative obligation), but also, in light of his duty to guarantee the full and free exercise of human rights requires that States adopt all appropriate measures to protect and preserve the right to life (positive obligation). This active protection of the right to life by the state not only involves its legislators, but also every state institution ... ".[119]

The IACHR Court has used a more subtle and careful language in addressing this issue, noting:

"If due process of law, with its set of rights and guarantees, must be respected in any circumstances, its observance is even more important when the supreme good that all human rights declarations and treaties recognize and protect is at stake: human life".[120]

In the same way, it points out that the recognition of other rights depends on safeguarding the right to life. "By not respecting the right to life, all other rights disappear, since the owner is extinguished."[121]

"The right to life is a fundamental human right, whose enjoyment is a prerequisite for the enjoyment of all other human rights. If not respected, all rights have no meaning. Because of the fundamental nature of the right to life, restrictive approaches are not admissible",[122] and "states have the obligation to guarantee the creation of the conditions that are required so that violations of this inalienable right do not occur".[123]

If not respected, all rights have no meaning. Due to this nature, restrictive approaches are not admissible. In accordance with article 27.2 of the Convention, this right form part of the non-derogable nucleus, since it is enshrined as one of those that cannot be suspended in cases of war, public danger or other threats to the independence or security of the States Parties.[124]

Likewise, the following paragraph is reiterated in the body of jurisprudence issued by the Inter-American Court of Human Rights itself:

"In virtue of this fundamental role assigned to it in the Convention, States have the obligation to guarantee the creation of the necessary conditions so that violations of this inalienable right do not occur, as well as the duty to prevent their agents or individuals attempt against it. The object and purpose of the Convention, as an instrument for the protection of the human being, requires that the right to life be interpreted and applied in such a way that its safeguards are practical and effective (*effet utile*)".[125]

On the other hand, the Inter-American Commission on Human Rights (CIDH) has been emphatic in recognizing the special nature of the right to life. In a decision adopted in 1996 expressly states:

(...) the Inter-American Commission on Human Rights must emphasize (...) that the right to life, understood as a fundamental right of the human person enshrined in the American Declaration and in various international instruments at a regional and universal level, has the status of *jus-cogens*.[126]

"The concept of *jus-cogens*» adds the IACHR derives from a higher order of norms established in ancient times and that cannot be contravened by the laws of man or nations".[127] According to the IACHR, in a more recent decision:

"The right to life is widely recognized as the supreme right of the human being and *conditio sine qua non* for the enjoyment of all other rights".[128]

The interpretation of conformity by article 31.1 of the Vienna Convention, of the aforementioned article 6.1 of the ICCPr, consists of "respecting ... (the) life" of its owner. That is the "object and purpose" of that norm, which means that it was established so that it really reached what it was persecuted for and not to be left without content.

In his second sentence and after a point in a row, "this right will be protected by law". And that "no one can be deprived of life arbitrarily", that is, in accordance with what was understood by arbitrariness on the date of the Convention and is understood even now, that is, that it is not an "act or proceeding contrary» to justice, reason or laws, dictated only by will or caprice".[129]

Particularities on the Paragraphs (9 And 10) Inexacts, Ambiguos Or Incongruent With Article 6.

Paragraph 9:

"9. Although States parties may take measures to regulate interruptions of pregnancy, such measures should not result in the violation of a pregnant woman's right to life or her other rights under the Covenant, including the prohibition of cruel treatment or punishment, inhuman or degrading. Therefore, legal restrictions on the ability of women to request abortion should not, inter alia, endanger their lives or subject them to physical or mental suffering in violation of Article 7.[130] States Parties must provide safe access to abortion to protect life and physical integrity. The health of pregnant women and in situations in which carrying a pregnancy to term would cause the woman substantial pain or suffering, especially when the pregnancy is the result of rape or incest or when the fetus suffers from a fatal deterioration. States Parties cannot regulate pregnancy or abortion contrary to their duty to ensure that women do not have to perform unsafe abortions. [For example, they should not take measures such as the criminalization of pregnancies by unmarried women or the application of criminal sanctions to women who undergo an abortion or against the doctors who help them to do so, when they are expected to increase significantly the use of unsafe abortions. Nor should States parties introduce humiliating or excessively burdensome requirements for women who wish to undergo abortion. The duty to protect the lives of women against the health risks associated with unsafe abortions requires States Parties to guarantee access for women and men, and adolescents in particular, to information and education about the options reproductive systems and a wide range of contraceptive methods. States Parties must also ensure the availability of adequate prenatal and post-abortion care for pregnant women." It cannot be proposed that the abortion be performed, due to certain circumstances of the fetus and in an ambiguous way, which can create confusion and violates the principle of penal taxation.

In combination with was previously mentioned with people with disabilities, this group (disabled people) has repeatedly denounced that the selection against embryos with disabilities directly damages both unborn patients, as well as adults and those already born. This community has qualified the measures of prenatal diagnosis and elimination of patients, not only as eugenic measures in general, but has denounced them as a genetic genocide.[131]

The current proposal promotes abortion only for cases of "severe disability", this type of measures is usually a euphemism that can lead to increasingly extreme positions that may end up being applied and even in an almost obligatory way, in all cases, of greater or lesser disability in the unborn, as Wasserman showed in 2012, using advanced techniques to prevent his birth.[132]

On the contrary, it is important to reaffirm that patients with disabilities contribute positively to society, to families, to their friends and even to the economy. They contribute not because of their disability, but "... because along with their disabilities come other characteristics of personality, talent and humanity that make disabled people full members of the moral and human community".[133]

It is important to mention that this vision against people with disabilities violates the United Nations Convention on the Rights of Persons with Disabilities, in particular:

Article 10 states that: "The States Parties reaffirm that every human being has the inherent right to life and must take all necessary measures to ensure effective enjoyment by persons with disabilities based on equity with others."

Article 25: "The States Parties recognize that persons with disabilities have the right to enjoy the best standard of health without discrimination based on their disability."

The *nasciturus*, in its different stages, (zygote, embryo, fetus), despite the degree of cellular and organ specialization, is vulnerable, fragile and dependent on another to perform their vital functions, unable to fully exercise their sensitivity, intellection and locomotion, that is, temporarily disabled. (It is not known if any of these disabilities will last over time or only be resolved after a maturation that takes time). Therefore, the *nasciturus* is entitled to legal protection by the State given their condition (temporary or permanent) of disability.

In this regard, it must be said that it is currently shown as an *endoxa*, as a common place, at least legally, in the current international legal frameworks. Currently, there is a rise in pro-people with disabilities movements for many other reasons, and that is another good argument for the rights of the *nasciturus*.

However, is it appropriate to consider the *nasciturus* as disabled? This admits at least two approaches. One strictly anthropological and another legal. Regarding the legal terrain, the Mexican law in force (General Law for the inclusion of people with disabilities, of May 30, 2011), following almost completely the text of the UN, defines the person with a disability as: "XXI . Person with Disability. Any person who, due to congenital or acquired reasons, has one or more deficiencies of a physical, mental, intellectual or sensory nature, whether permanent or temporary and which, when interacting with the barriers imposed by the social environment, may prevent their full and effective inclusion, on equal terms with others." Under this definition, effectively, the *nasciturus* is perfectly defined as a person with temporary disability (sensory, mental, locomotive, without freedom to feed or fend for itself), so it can benefit from the protection that these frames offer. Thus, all eugenic practice becomes a formal practice of discrimination, especially when the legal subject in question is even more vulnerable because of their age and their impossibility of autonomy and individual independence in the most basic planes of survival.

But let's see, the anthropological problem behind the legal problem. Following closely the critical iuspositivism of Luigi Ferrajoli,[134] there is a fourfold relationship between the Law and the "differences": a) Hobbesian, where there is a legal indifference of differences are not protected or violated, they are simply ignored. b) legal differentiation of the differences. Some are valued over others. c) legal homologation of the differences. The differences are suppressed in order to maintain an abstract equality that ignores them. d) legal assessment of differences, where differences are protected, the equal right of all to the affirmation and protection of their own identity is sought, by virtue of the equal value associated with all the differences that make each person an individual diverse from all others and from each individual a person like all others.

Ferrajoli's guarantee approach can be complemented with the Levinasian theory of vulnerability and reinforce that there must be a legal assessment of this difference that occurs on the *nasciturus*. In fact, the person before birth and a long time afterwards is an independent but extremely fragile organism.[135] Its difference based on vulnerability makes it a specific subject of law, it must be assisted by a special guarantee, since, in case of potential conflict of rights, its difference makes it the weakest party, and therefore, the privileged party.

For Levinas, the vulnerability of the other is the obverse of the same reality whose reverse, for me, is the imperative whose negative formulation is not to kill[136] and the affirmative is, in Hebrew, *hineni*, "here I am", that is, a permanent responsibility for doing everything that is on our part to make the other live.

On the other hand, the good effect should not be achieved through the bad; the presumed freedom –is updated with a component of responsibility of the mother– and cannot be proclaimed unambiguously, since it affects a third party or, at least, a value such as life, different from the rights, values and interests of the pregnant woman herself, understanding that circumstances that are not planned should be addressed with education and social support. Likewise, the penalties considered should not be criminalized, but implemented with a perspective of restorative justice and psychosocial support.

"The natural bond of the *nasciturus* with its mother, is based in a relationship of special nature of which there is no parallel in any other social circumstance", abortion, should be understood as a social, family and state failure; For its part, the European Parliament and the Consultative Assembly of the Council of Europe establish that abortion must be eradicated.[137]

Abortion has irreversible consequences; whose social dimension affects the foundations of relational coexistence. But it also has a biological dimension, so it must be considered from the perspective of biology, medicine and health.

The Commission on Population and Development[138] pointed out:

"12 ... reducing the use of abortion by increasing and improving family planning services and, in cases where abortion is not illegal, adequate training and equipment for health service providers and other measures to ensure that abortion is safe and accessible, recognizing that in no case should abortion be promoted as a method of family planning or prevention and treatment of sexually transmitted diseases ..."

As an alternative to this policy, it would be necessary to carry out a series of social policies for maternity protection and specific support to women who have difficulties in continuing pregnancy and are forced, against their wishes, to make the decision to abort due to the lack of resources or third-party pressure, being itself a real situation of violence. As well as access to justice, where the criminal is really punished, providing a useful effect of rights.

The objective is to protect "life, both of the woman and the unborn, as well as the proper development of pregnancy and the resolution of conflicts." This is carried out in an extraordinarily delicate moment for the pregnant woman: when she has already expressed her decision to undergo an abortion, either because her life seems to be in danger, or because the pregnancy has been the result of sexual assault.

On the other hand, concepts such as legal or voluntary interruption of pregnancy, lack a definition or contents of a standard, these concepts are an euphemism, since when establishing the term interruption (action and effect of interrupting), and interrupt is to cut the continuity of something in time,[139] which for the case is understood as "a temporary suspension of the pregnancy", it can be illustrated with any intrauterine intervention such as a bifid spine surgery, megabladder, intrauterine transfusion, etc., different from abortion that does not interrupts, but ends pregnancy.

In general, the legislation must always consider three aspects: guarantee the protection of all legal rights in question, promote the possible good and reduce the possibility of double effect that is sometimes inevitable.

The jurist as well, has the duty of a correct and responsible exercise of fairness, prudence, calm deliberation, and authentic practical wisdom.

Resolution 1607/2008 adopted in the Parliamentary Assembly by the Council of Europe, states that the evidence shows that the adequate strategies and policies regarding sexual health, including education for young people in sexuality and relationships, appropriate to their age, leads to less recourse to abortion.

The legalization of abortion, together with social pressures and ideological interest of specific groups, can be a pressure factor on women and motherhood, and by establishing a new right, it can justify a threat to the *nasciturus*.

Physicians may face pressure to recommend prenatal genetic studies and even abortion, since they are the ones who can determine the probabilities of congenital defects of the *nasciturus* in its first weeks of development, these studies that are still probabilistic, combined with the possibility to abort freely in any given week, generate a new problem of pressure on the doctor to recommend abortion at the mere risk of a diagnostic error. Considering the case that abortion is permitted, the probabilities of the various prenatal studies to know the health of the child and the social standards of the biologically desirable child (eugenics), pressure is placed on the parents or the pregnant woman and more so the doctors under a supposed malpractice within the so-called "wrongful birth", accusing the doctor, that by not having recommended the prenatal genetic study, the parents missed the opportunity to abort the *nasciturus*, which was born with malformations, as was the case with Perruche in France.

In contrast, the promotion of maternal health has been a key concern for public health policymakers worldwide on the recommendation of the United Nations (UN) that proposed the Millennium Development Goals (MDGs). The fifth goal focuses on improving maternal health; The UN required all member states to reduce maternal mortality by 75% by 2015. However, as of 2015, the reduction of maternal deaths has not been achieved and is still far from this figure. New complementary social or public health policies have been promoted to support a new post-MDG agenda, but to be effective they must be supported by scientific evidence.

For example, maternal mortality in Mexico has decreased globally by 22% in the last decade, from 48.6 to 37.7 per 100,000 live births. Abortion has never been the main causes of death. In fact, in a detailed study published in the International Journal of Women's Health, about 98% of maternal deaths were unrelated to an illegal induced abortion, which has an occurrence of approximately 1 per 100,000 live births.[140] The main causes of mortality were hemorrhage, hypertensive syndromes of pregnancy, indirect causes and other external causes unrelated to pregnancy. Regarding maternal deaths and the legal status of abortion, a detailed investigation of maternal deaths in the 32 Mexican states divided into two groups was published in the British Medical Journal Open, based on the penal codes in force in each state: 14 states (including Mexico City) classified with more permissive legislation and 18 states classified with less permissive legislation.[141] Interestingly, it was observed that states with less permissive legislation exhibited on average 27% fewer total maternal deaths and 47% fewer induced abortion deaths compared to states that exhibited more permissive legislation for the period from 2002 to 2011.

Through multivariate statistical analyzes, the authors demonstrated that before the abortion laws, the differences between states were explained by other factors known to impact on maternal health such as the level of education of women of reproductive age in each state, state fertility rate, access to prenatal care, professional delivery care, availability of obstetric emergency units, safe drinking water and sewage coverage, prevalence of intimate partner violence against women and individual risk factors. The authors stressed the need to control for these factors in other studies before concluding that abortion laws may have some effect on maternal mortality rates.[142] No study controlled by multiple confounding factors has shown that more permissive abortion legislation has an independent effect on the rate of maternal death.[143] In the investigations conducted in Mexico,[144] as in another natural experiment previously conducted in Chile[145] and published in the journal PLoS One,[146] it was concluded that a more permissive abortion legislation has no direct impact on maternal mortality rates and does not diminish them either, being its effect rather null.[147]

Maternal mortality is not increased by the legal restriction of abortion, nonetheless it is related to the lack of access to many basic services and other social factors that are currently neglected in public policies impacting human development indicators such as:

— Lack of women's access to education.
— Lack of free nutrition programs for pregnant women living in poverty.
— Lack of availability and proximity of emergency obstetric units.
— Lack of access to drinking water.
— Absence of sewage systems.

It is known that taking care of these factors is fundamental to generate favorable conditions for a decrease in maternal mortality. It has been scientifically confirmed that these factors have a serious impact on maternal deaths, so they must be comprehensively addressed by those responsible for creating and implementing public health policies taking into account indicators of human development.

In the elaboration of public health policies, it is very important to consider that the legal status of abortion is not the central issue for a leading-edge discussion regarding women's well-being, rather, it is hostile and not the solution for all cases. The main issue to be addressed in order to have an impact on better health conditions for women of reproductive age is attention in different scopes of development. In the investigations aforementioned, the authors, experts in epidemiology, public health, obstetrics, gynecology, medicine, surgery and sociology recommend seven specific interventions:

- Increase access to prenatal care and professional delivery care in health institutions.
- Increase the number and access to emergency obstetric units.
- Expand specialized diagnostic centers and prenatal care for high-risk pregnancies, incorporating other medical specialties.
- Develop pre-conception counseling programs to promote healthy pregnancies before age 35.
- Expand and strengthen public policies aimed at increasing years of education in the female population.
- Improve the detection of violence against pregnant women during prenatal check-ups and intervention by skilled health professionals.
- Reduce disparities in human development indicators by increasing access to drinking water and sewerage.

Finally, as it has been discussed and made known in previous lines, the following statements can be made –even through common sense– regarding the embryo's individuality, diversity and differences with the mother's body:

1. It has a human genome different from that of the mother and that of the father. It has a unique proteome and individual epigenetic conditions, being a different being with regard to his parents.

2. It may be of a different sex than the mother.
3. It may have a different blood group than the mother.
4. It can be sick and the mother healthy.
5. The mother can be sick and the embryo healthy.
6. Another evidence of the incongruity of considering the embryo part of the mother is the fact that when the embryo is born, the mother is not left with any functional deficiency. If the embryo were part of the mother, after the abortion or delivery, the woman would have some functional insufficiency, which should be compensated, or she would be left with mutilation or decompensation for life. None of this happens, the functionality of the woman is independent of the existence of this other human being, who is his son.
7. Medically speaking there is the specialty of gynecology and obstetrics for the mother and perinatology for the embryo and the fetus, since they are different beings, with different characteristics from the medical perspective.
8. The embryo can live outside the maternal body, as in *in vitro* fertilization, done in a container that is only a glass device.
9. The embryo can live in a body other than the mother's, as in assisted reproduction technologies with a surrogate womb.
10. Immunological evidence. The embryo is so different from the mother that an immune response against the embryo usually starts. Most of the time that immune response is suppressed by complex phenomena, where the placenta and the entire maternal and embryonic immune system are involved.
11. It does not seem logical to grant the embryo the substantiveness of the mother to sustain the insubstantiality of the embryo.[148]
12. Embryos can be maintained in cryopreservation for a long time and be transferred later.

Paragraph 10

"10. [While recognizing the fundamental importance of human dignity in personal autonomy, the Committee considers that States parties should recognize that people who plan or attempt suicide can do so because they are going through a momentary crisis that may affect their ability to make irreversible decisions, such as ending his life. Therefore, States should take appropriate measures, without violating their obligations under the Covenant, to prevent suicides, especially among individuals in particularly vulnerable situations. At the same time, States Parties [may allow] [must not prevent] medical professionals from providing medical treatment or medical means to facilitate the termination of the lives of [catastrophically] affected adults, such as the mortally injured or terminally ill, who experience severe pain and physical or mental suffering and wish to die with dignity. In such cases, States Parties must ensure the existence of sound legal and institutional safeguards to verify that medical professionals comply with the free, informed, explicit and unambiguous decision of their patients, in order to protect patients from pressure and the abuse."

The new paradigm of legal positivism is an object of reflection in the current collapse of society, by the disappearance of otherness and strangeness.[149]

The hypertrophic approach of present-day systems, information systems, communications, production[150] and now of the law, is losing its human imprint, seeking to justify and nourish human passions, burying the nobility of the personal spirit that limits all people of individualistic self-destruction, rather, we must build on differences and human empathy.

We punish ourselves, with the violence of dissuasion, pacification, neutralization, control, of the soft violence of extermination. Therapeutic, genetic or communicational violence: violence of consensus, which now impacts on ideologies reflected in the laws. This violence is viral, in the sense that it does not operate frontally but by consanguinity, by contagion, by chain reaction and from the first moment it attacks our entire immune system.[151]

Where now Nietzsche's sovereign man is about to become a mass reality: there is nothing above him that can indicate who he should be, because he considers himself the sole owner of himself. "We have invented happiness; the last men say"[152]

In this way, he is only subject to himself and any limitation to his immanentist possibilities is aggression and intolerance, permeating now as supposed human rights, trying to captivate as a siren song, subtly not mentioning that it is encouraged as euthanasia or assisted suicide.

In this regard, the World Health Organization (WHO) defines it as that "action of the doctor that deliberately causes the death of the patient".[153] and, the World Medical Association in the Declaration on Euthanasia establishes it as the deliberate act of ending the life of a patient, even if it is by his own request or at the request of his relatives, which is contrary to ethics. This does not prevent the doctor from respecting the patient's desire to let the natural process of death take its course in the terminal phase of illness.[154] Disrupting doctors deontological positioning of attending life, personal integrity and health of human beings, with the best possible means, alleviating any type of disease and alleviating their suffering and their family's anguish, thus respecting their dignity.

At this point, physicians will have to put aside their conscience and subsequent objection, to become an executioner "certified" by medicine, demanding that his own will becomes an automaton of the wishes of a third party and coerced by a legal norm, without really analyzing as scientist that takes care of human health, or if there is a vice in the patients consent, derived from depression, disability, abandonment or other vulnerable circumstance, as well as seeking to offer the patient new therapeutic options available from the most recent advances of medicine.

In this way, it is clear that euthanasia goes against human life, using the intervention of a third party, being the antithesis of the "Right to life", recognized as a primary human right. In that strong sense of this human right, comes to tell us that the expression "have a right" means that another or other people have a duty towards its safeguard and the opposite would be unfair.

To ponder the degree of precision of a human right, not only logical-deductive associations can occur, but also justificatory or instrumental associations that belong to the world of practical reasoning can occur and are impossible to grasp in the formal ties of logical-deductive reasoning. Raz[155] calls them "core-rights", which are those rights constituted by the normative system, as distinguishable from derivative-rights that are those that can be considered to be implied by the core-rights and therefore, are susceptible of being obtained deductively from these; the right to life is one of them, not the right to die, which would be the opposition (antinomy).

For a right to have the character of Human Right, some formal structural features are required, not depending on consensus.

The first that is discoursed is "universality"; It means that they are ascribed to all human beings and requires, that specific circumstances, conditions o contexts are to be ignored, because such rights have a vocation to be ascribed to all. It suffices that the minimum requirement of being "human being" is met, in that sense, we have to separate human rights from the scope of the positive legal system. Because in effect, we do not talk about rights that some have, and others don't, depending on the legal system. We all share the same rights

Therefore, the characteristic of human rights is to establish the existence of general obligations and not so much on special obligations, that is, obligations of all and not so much on merely positional obligations. Obligations tend to be differentiated into negative "not doing, omitting" and positive ones, they are obligations to do, to perform an action and the first one is relational coexistence, based on the common good.

The second formal feature is the presumed "absolute" character of Human Rights. This idea makes a direct reference to what in general terms has been called its importance,[156] and what lies under that condition is the idea of strong moral demand or, as Richards says: "the urgent, demanding and intransigent nature of human rights".[157] Now, if it is said that the right to life is not absolute, it is by its weighting on the same level, in that way is how is legitimate defense is safeguarded, derived from an unjust act.

Human rights are the kind of strong demand that they are, not because they have corresponding obligations, but on the contrary, the obligations are strong precisely because human rights carry a constitutive force by themselves.[158] And if that force does not derive from the obligation component, it must necessarily derive from the other component, that is, from the good, from the qualified assessment of the situation or state of affairs that it attempts to guarantee.

The right to life is linked to the ontological principle of the instinct of conservation, which must be safeguarded on the basis of human relational coexistence, just as they are protected in palliative care.

The third formal feature is that they are "inalienable", for the majority of those who have analyzed the issue, it means that it cannot be taken or stolen from the person, and the rights are to be inalienable because all without exception, are holders of them (and therefore no one could be deprived of them). Those two features are related especially with the universal and absolute character of Human Rights, and not with the idea of inalienability in the strict sense.

When Grotius designs the passage from the state of nature to civil society, it is posed, starting a tradition that will be legendary, the problem of what natural rights individuals renounce when entering such a society. For him there is no doubt that individuals renounce the natural right of self-defense or natural right to punish but situates the problem in the broader framework of the renunciation of freedom.[159]

It is about the problem of giving up certain rights on the part of its own owners. What Grotius is suggesting is that, even if one can logically think of a possibility of absolute renunciation in the very notion of voluntary and free pact, one can only choose the soft interpretation, or as it has been called using Quine's idea, the charitable interpretation that individuals could not do such barbarity.

If we accepted the former idea, slavery would come to be justified by a theory of natural rights. We cannot, therefore, interpret the pact in that way. And from this arises the issue of the inalienability of basic rights: its formulation means that we cannot think of them as something that can be renounced by the owner's own will. What American theorists wanted to do, was establish an absolute restriction to the idea of consenting to be deprived of a basic right. They thought, on the contrary, that one could never speak of rights in that sense, the kind that would say that an individual act of consent supposed their disappearance.[160] And this cannot be identified, as it hastily has been done, with the idea that human rights cannot be justifiably displaced.

The formal meaning here is how to express the idea that human rights are inalienable even by their holders.

In that sense when speaking of universality, we have seen how a human right supposed the affirmation of a good of such importance for the individual that this constituted a sufficient reason to impose obligations on all others, and the absolute, is the force that given to that right towards all people, and its inalienability as the application of the normative technique of the obligation or immunity to the holder of the right. Just as everyone has the obligation to respect each other's right or lack the power to alter that right, the owner himself is obliged to respect his own rights being, we could say, immunized normatively against himself.

Finally, according to "Noëlle Lenoir, dignity is the source of all rights, therefore it is a pre-legal concept; it can be considered as the foundation on which the rights of the human being are based. In this same position, Jürgen Moltmann points out: "The root and the common bond of the various human rights is human dignity.".[61] Inherent value to the human person, for his axiological position.

The legalization of euthanasia and assisted suicide will result in unjust structures, which consist of the distribution and stratification of people, groups and various elements within a social organism, so that unfair situations are consolidated. Circumstances of discrimination, abuses, and justifications without consent of all the co-implicated, or because they are not in a position to make the correct decisions, acting against human dignity and in a regressive manner within human rights, also creating a right not contemplated in any convention, rather an antinomy by consensus of a few.

Moreover, it is contrary to the *lex artis ad hoc* of medicine, as observed, among others, in the following instruments:

Principles of European Medical Ethics. Doctor's Commitment

Helping the dying

Article 12º. Medicine implies in all circumstances constant respect for life, for moral autonomy and for the freedom of choice of the patient. In case of incurable and terminal illness, the doctor can limit himself to alleviate the physical and moral suffering of the patient, administering the appropriate treatments and maintaining, as much as possible, the quality of a life that is finished. It is obligatory to attend to the dying person until the end and act in a way that allows him to preserve his dignity.

Hippocratic Oath

I will apply my treatments for the benefit of the sick, according to my capacity and good judgment, and I will refrain from doing them harm or injustice. Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course. Similarly, I will not give to a woman a pessary to cause abortion. (...)

Recommendation 1418 (1999) Protection of human rights and dignity of the terminally ill and dying. The text of this Recommendation was adopted by the Assembly on June 25, 1999 (24th Session).

In principle seeks to protect the dignity of people and all rights that are inalienable. It seeks to provide an adequate means that allows the human being to die with dignity. This recommendation is based on technological advances that can be applied without taking into account the quality of life of the patient or his decision on the treatment that may be applied, prolonging life unnecessarily or delaying death, maintaining this is the suffering of both the patient and the family.

In 1976 a resolution of the Assembly was issued in which it is stated that "prolonging life must not be, in itself, the exclusive goal of medical practice, which must also be concerned with the alleviation of suffering". Subsequently the European Convention for the Protection of Human Rights and the Dignity of the Human Being set the principles affirming the specific needs of the terminally ill.

The rights derived from the dignity of terminally ill patients are affected by the difficulty to access palliative care, lack of treatment of their psychological, social and spiritual needs, artificial and disproportionate prolongation of the dying process, insufficient support and assistance to family members, lack of training of health professionals, insufficient allocation of financial resources for assistance and care for the terminally ill, discrimination, and stigma towards the sick.

Derived from the above, the Assembly resolved that countries should incorporate legal and social protection in favor of the terminally ill for circumstances such as: dying subjected to pain, prolongation of the death process; as well as social isolation and restriction of life support physicians for economic reasons.

In this regard, it was recommended that the members of the Council of Europe should respect and protect the dignity of the terminally ill in all aspects, adopting measures aimed at eliminating the injustice done to the rights previously affected.

Declaration of the World Medical Association on euthanasia. Adopted by the 39th World Medical Assembly, Madrid, Spain, October 1987.

Euthanasia, that is, the deliberate act of putting an end to the life of a patient, even if by choice or at the request of family members, is contrary to ethics. This does not prevent the doctor from respecting the patient's desire to let the natural process of death run its course in the terminal phase of his illness.

Declaration of the World Medical Association on the care of patients with severe chronic pain in terminal diseases.[162]

Introduction

The care of patients with terminal illnesses with severe chronic pain must provide a treatment that allows these patients to arrive at end their lives with dignity and motivation. Analgesics, with or without opium, when used properly are effective in patients with terminal diseases. The physician and other personnel who care for patients with terminal illnesses must clearly understand the mechanisms of pain, the clinical pharmacology of the analgesics and the needs of the patient, their family and friends. It is also imperative that governments ensure the supply of medically necessary amounts of opioid analgesics, for their proper application in the control of severe chronic pain.

In that same means there are: The Principles of the Clinical Treatment of Severe Chronic Pain, the Resolution of the World Medical Association on Human Rights. Adopted by the 42nd World Medical Assembly, Rancho Mirage, California, USA, in October 1990, and amended by the 45th World Medical Assembly, Budapest, Hungary, in October 1993 and by the 46th WMA General Assembly, Stockholm, Sweden, in September 1994 and by the 47th World Medical Assembly, Bali, Indonesia, in September 1995, the Venice Declaration of the World Medical Association on terminal illness. Adopted by the 35th World Medical Assembly, Venice, Italy, October 1983, etc. None of these speak of assisted suicide or euthanasia.

Rather, what should be promoted is palliative care, whose objective is the improvement of the patient's circumstances, in the full sense; that is, understanding not only the physical dimension, but also the psychological, and spiritual dimensions.

In this regard, the World Health Organization (WHO), adopted in a key document for the development of palliative care published in 1990, the definition proposed by the European Association of Palliative Care as the "total active care of patients whose disease does not respond to curative treatment. The control of pain and other symptoms and psychological, social and spiritual problems is paramount". It stressed that palliative care should not be limited to the last days of life but should be progressively applied as the disease progresses and according to the needs of patients and their family.

Subsequently, the WHO has expanded the definition of palliative care: **"An approach that improves the quality of life of patients and families who face the problems associated with life threatening diseases, through the prevention and relief of suffering through the early identification and impeccable evaluation and treatment of pain and other physical, psychological and spiritual problems".**

Regarding children, the World Health Organization (WHO) defines palliative care as: "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease".

Palliative care is, in addition, the organized response that covers the needs of patients and family members who go through this stage of the disease that we call terminal, a time also when the disease is no longer controllable and in which multiple somatic symptoms appear and a progressive deterioration associated with emotional changes of adaptation to the loss of functions and roles that affects both patients and family members.

Initially palliative care focused on cancer patients, currently the model is applicable to patients with advanced chronic diseases.

Palliative care improves the quality of life of patients and families facing life threatening diseases, mitigating pain and other symptoms, and providing spiritual and psychological support from the moment of diagnosis to the end of life and grief.

In general terms, palliative care:

— Relieves pain and other distressing symptoms;
— Affirms life and consider death as a normal process;
— Do not attempt to accelerate or delay death;
— Integrate the psychological and spiritual aspects of patient care;
— Offers a support system to help patients live as actively as possible until death;
— Offers a support system to help the family adapt during the patient's illness and in their own grief;
— Makes use of a team approach to respond to the needs of patients and their families, including emotional support in grief;
— Improve health or at least significantly alleviate disease and improve overall well-being, with the possibility of also positively influence the course of the disease;
— Can be given at an early stage of the disease, along with other treatments that can prolong life, such as chemotherapy or radiation therapy, including the necessary study to better understand and manage distressing clinical complications.

Mass media expose, in a tacit way, the concept that a person has the right to dispose of their own life through the option of requesting euthanasia or medically assisted suicide; it identifies it as the maximum act of respect for the individuality and autonomy of the person and, in this way, of human dignity. Additionally, it presents the benevolent figure of those who apply the lethal drug as someone who, understanding that nobody can "... impose the obligation to continue living to someone who, because of extreme suffering, no longer wishes ...",[163] grants him the "gift of death", as a relief to suffering in life, thus turning it supposedly into a benevolent act.

There is a fundamental error of concept in the argument, identifying as the central value in this act the potential individual capacity (and to a certain extent, the right) to decide on death, instead of strengthening that the maximum value of man is life[164] and that death is part of life itself. This faulty concept derives in multiple media actions to justify this act and give it an air of congruence, an act perceived as of maximum benevolence.

This approach seems to give a strong and irrefutable argument for the attitude of trying to control the conditions of death in terminal patients or in extreme suffering. Perhaps this same social pressure and cultural perception has caused countries like the Netherlands to have euthanasia as a legal option to end a life considered unworthy because of extreme and uncontrollable suffering.[165]

In 2012, the Dutch researcher Bregje D. Onwuteaka-Philipsen published an analysis of the practice of euthanasia in his country.[166] He found that, in 2005, 1.7% of the causes of death were due to euthanasia, a figure that reached 2.8% in 2012; 77% of the cases were attended by doctors, 56% of the patients asked for it because of a feeling of loss of dignity and 47% for untreatable pain.

The previous article shows that this concept of the power of decision over dying, interpreted as dignified death, can become a medical practice within easy reach, with argumentation and methodolog, clearly influenced by the "technological imperative" that Jonas Hans described in 1979[167] to consider that everything that is technically possible is ethically demandable, and with a clear danger to the exercise of medical ethics.

Another Dutch author, Zylicz, studied terminally ill patients and borderline situations, and identified five causes for which patients ask for euthanasia,[168] known as the ABC of euthanasia applications:

A. Afraid (fear)
B. Burn-out (emotional wear)
C. Control of Death (wish to control death)
D. Depression
E. Excruciating pain (unbearable pain)

All these causes have to do with an affected emotional state and a behavior consistent with emotional disturbance. It immediately highlights the point C of the list of Zylicz: desire to control death, since it is the same argument used by organizations that support so called dignified death and promote the practice of euthanasia. As a complement to this observation, we cannot leave aside the very interesting contribution to the field of end-of-life care by Dr. Elisabeth Kübler-Ross, a Swiss-American psychiatrist who through the Kübler-Ross Model, identified five phases of the emotional reactions of terminally ill patients:[169]

1. Denial and isolation
2. Anger
3. Bargaining (negotiation)
4. Depression
5. A cceptance

In light of these phases in the process of facing death, it is again observed that the arguments of the organizations mentioned are challenged in the third point, trying to negotiate the situation of death, alleging the utopian ability to control it.

It is clear that death is inevitable. There is no freedom of decision in this act, it will happen sooner or later. It is also clear that the argument that advocates a “right to die” using euthanasia as a tool is based on an *emotional reaction*, which is perfectly normal for patients who face the news of the end of their life. This emotional basis is what guides the creativity of the film scripts and generates empathy in the viewer before the protagonist who suffers inexorably, clouding the analysis of the fundamental arguments before the death process, where it should be understood that, in death, "... *the only thing in which freedom intervenes is the attitude adopted before it*".[170]

Zylicz himself has postulated that euthanasia is an "easy way out", which diminishes the doctor's creativity to look for solutions or new options in terminal patients,[171] but not only that, but it also makes it difficult to understand the true role of personal freedom in the face of death, keeps the doctor from understanding death as a personal, cultural and religious event,[172] not as a scientific event. At this point, the concept of accompaniment in the process, alleviating pain and anguish, and integrating psychological-spiritual aspects of the patient, justifies that the right tool for the defense of a dignified death is, precisely, palliative medicine.[173]

Rather, an "*ethical requirement*" should be pursued, not stubbornly looking to die, but the way of living the process of dying.[174] These ethical demands seek to reaffirm the dignity of the person at this stage, according to LG Blanco[175] they are: a) attention to the dying with all the means that currently medical science has to relieve their pain and prolong their human life; b) not deprive the dying person of dying as "personal action", dying is the supreme action of man; c) free death from the "concealment" to which it is subjected in today's society; d) organize an adequate hospital service so that death is an event consciously assumed by human beings and lived in community; e) favor the experience of the human-religious mystery of death, religious assistance in these circumstances takes on special importance.

The debate takes an optimal course starting by understanding death as a human act, where the individual does not remain passive before it, but practices freedom as the attitude to face the death process, that is; the right to a dignified death is the right to live one's death. This concept is based on the Judeo-Christian tradition, but it is perfectly valid to understand the concept that death is invariably a constitutive part of life and must be lived.

Therefore, the stream of personalist bioethics emerges as a fundamental tool in the recognition of dignity as a person, based on its human rights, which cannot be denied, are universal and are inalienable. Meaning that no one can decide to attempt against life, even if it is their own: there is no such thing as a "right to die".[176]

In this context, the principlism approach of bioethics does not fully cover the situation before the end of life and may offer false arguments, as stated at the beginning of this text. The bioethical foundation in these cases is closely linked to biolaw aspects, since it involves at least five ethical principles in the care of these patients,[177] the first is the principle of *truthfulness,* as the foundation of trust in the patient-patient relationship, and that represents the foundation of the four classic bioethical principles of principlism, (beneficence to the patient and family, facilitates the participation in the decision making –autonomy–, can be postponed in case the patient is not able to receive the news –nonmaleficence–, nevertheless information should always be handled with the truth –justice–); the second is the principle of *therapeutic proportionality*, where there is a moral obligation to implement the measures that have the proper proportion between the means used and the foreseeable overall result;[178] the third is the principle of *double effect*, since, in attempting to keep the patient pain-free, there may be a risk of deep sedation or even death;[179] the fourth is *prevention*, which is a medical duty to act prudently and pertinently before the appearance of complications or potential symptoms; the fifth and last is the principle of *nonabandonment*, which prevents the doctor from evading dealing with an element of life itself, death, and confronting it, arguing that "there is nothing more to offer," since it is contrary to proper attitude; when there isn't a cure, the person can be accompanied and comforted.[180]

A central point in the subject of euthanasia and assisted suicide is the pain that is difficult to treat, in this regard it is proper to point out that pain is defined as "an unpleasant sensation and an emotional experience associated with a current or potential tissue damage", according to the International *Association for the Study of Pain*, (ASP).[181] The stimulus related to injury of a tissue activates painful circuits that can be resolved over several days or weeks, however, the resolution of the damage may not occur at all generating a persistent stimulus and a state of chronic pain. All of the above immersed in a subjective emotional experience of «wear» for those who go through this suffering.[182]

Chronic pain, then, extends beyond 3 to 6 months and has a severe psychological component.[183, 184] Current theories evaluate if chronic pain is independent of the tissue injury, reflects a chronic illness or a chronic painful state.[185]

The evaluation of pain allows to elucidate its etiology and establish a treatment strategy.[186] For this, it must include the sensory and affective qualities of the pain, as well as its intensity, its temporal pattern and effectiveness of previous treatments.[187]

The mechanisms of chronic pain are complex and in constant study, however, in recent years there have been truly remarkable advances in the management of it, which has significantly reduced the group of patients with "untreatable pain", allowing more effective approaches to pain in these patients. The following is a current overview of interventions for pain management.

In this regard, currently there has been progress in current therapeutic interventions for pain. There is an "analgesic ladder" well known in pain management clinics, consists of progressively escalating analgesics to find the most effective, however, it is a practice with a tendency to disappear, since it seeks to address pain by its mechanism, instead of considering response to analgesics.[188]

Additionally, it is well known that drugs alone do not offer the best benefits,[189] a multimodal approach is required, including; medication, physical rehabilitation, changes in lifestyle, psychological therapy, surgery and complementary medicine,[190] such as:

a) *Physical Therapy*. There is some evidence of short and medium-term benefit in the use of physical strategies for pain management.[191]
b) *Psychological Therapies*. They are fundamental to a proper approach, since the feeling of rejection, emotions, and behaviors against chronic pain directly influence the subjective experience of it, and thus, in their perception of severity, which could be exaggerated with hypervigilance.[192] Cognitive behavioral therapy is effective in dealing with pain and self-modulating the experience of pain in an appropriate way.[193] There is also a clear relationship between depression and chronic pain, so this point is fundamental in the approach of the patient with chronic pain.
c) *Pharmacotherapy of Chronic Pain*. There is analgesic therapy through different agents, from non-steroidal anti-inflammatories to opioid drugs, the latter with greater analgesic action due to their pharmacological properties.[194] The risk of abuse and dependence is a worrisome situation as a result of the poorly supervised employment of these strategies, which is potentially fatal.[195] A proper follow-up in their use makes them a tool and of great value in terminal patients, with clear benefit in most cases.[196] Other adjuvant drugs are antidepressants (tricyclics, selective serotonin reuptake inhibitors and dual antidepressants) that modulate nociceptive perception pathways, allowing to reduce the chronic painful stimulus,[197] as well as other neuromodulatory drugs.
d) *Classical Interventional Therapy*. The infiltrations are invasive techniques where an injection of drugs in the injured or affected areas allows a radical improvementb in pain management, however, their effect is temporary and usually they are expensive.[198]
e) *Advanced Interventional Therapy*. They are invasive advanced neuromodulatory techniques which have come to be considered as a first line intervention in severe and chronic pain.[199]

Spinal Cord Stimulation (SCS). An electrical stimulator implanted surgically under the skin sends electrical signals to the spinal cord, using minimally invasive techniques, causing a mild and pleasant paresthesia in the underlying painful region. The patient has control of the device programming the electrical stimulus with very favorable responses, the downside is the surgical risk, which, in expert hands, are minor. In cost-benefit studies, despite its high price, its use is favorable versus the expense of other therapies and repeated hospitalizations for pain management.

Intrathecal Drug Delivery Devices (IDDS) This are drug infusion pumps in the spinal canal that provide the amount of analgesic medication necessary for pain control, controlled by the medical team and sometimes by the same patient,[200] they are very effective in pain management in cancer patients or patients with chronic pain.[200]

Finally, there is also novel trends in pain management. One of them is to address pain not by the scale for the need of an interventional procedure or the use of pain specific drugs, but rather by neurophysiological pain. Thus, it will be possible to modulate, for example, voltage-dependent ion channels (sodium, calcium, potassium), which are responsible for generating cellular membrane action potential in nerve cells of painful pathways. Similarly, ligand-dependent channels and receptors (NMDA), or the transient potential receptor TPRV1, are being investigated for the development of specific modulatory drugs.

The immunomodulation of anti-inflammatory cytokines also offers a promising outlook in the management of chronic pain, such as interleukin 10, although the technical and pharmaco-biological difficulty of these have not yet permitted their routine use for pain.

There are also therapeutic strategies to reduce the levels of neurotransmitters that potentiate the pain pathways in GABAergic networks, as well as signaling of lysophosphatidic acid, related to chronic pain in nociceptive pathways and its modulation by monoclonal antibodies or inhibitors of its own modulating enzyme, Atx.[200] Gene therapy has also provided options to transfer "therapeutic genes" by genetic vectors enabling the expression of proteins or peptides in target cells of nociceptive pathways, such as opioid genes, anti-inflammatory cytokines or on expression or negative regulation of ion channels,[201] or, thanks to the recent identification of «pain genes» (Scn9a, Nav1.7, Trpa1, etc.), the expression of these genes could be selectively blocked, facilitating the management of chronic pain syndromes and allowing a new paradigm in the treatment of patients with chronic pain,[202] potentially eliminating the concept of "intractable chronic pain".

As it is stated in this document, establishing criteria contrary to the right to life is not adequate and much less proportional in relation to current scientific advances, human dignity and the global perception of those represented by the Committee's vision. The Committee should be careful not to create antinomies in their interpretation and chaos into the interior of many countries not compatible with their position.

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[7] 22 de noviembre de 1969, san José de Costa Rica.

[8] Consejo de Europa el 4 de noviembre de 1950.

[9] Sentencia (Excepciones Preliminares, Fondo, Reparaciones y Costas) Caso Artavia Murillo y Otros ("Fecundación in Vitro") vs. Costa rica, de 28 de noviembre de 2012, párrafo 176.

[10] Tedh, *Caso Vo. Vs. Francia*, (No. 53924/00), GC, Sentencia de 8 de julio de 2004, párrs. 75, 82, 84 y 85. (Unlike Article 4 of the American Convention on Human Rights, which provides that the right to life must be protected "in general, from the moment of conception», Article 2 of the Convention is silent as to the temporal limitations of the right to life and, in particular, does not define «everyone" […] whose "life" is protected by the Convention. The Court has yet to determine the issue of the "beginning" of «everyone's right to life» within the meaning of this provision and whether the unborn child has such a right.» […]

[11] Tedh, *Caso A, B y C vs. Irlanda*, (Nº 25579/05), Sentencia de 16 de diciembre de 2010, párr. 237. ([T]he questions of when the right to life begins came within the States' margin of appreciation because there was no European consensus on the scientific and legal definition of the beginning of life, so that it was impossible to answer the question whether the unborn was a person to be protected for the purposes of Article 2. Since the rights claimed on behalf of the foetus and those of the mother are inextricably interconnected […], the margin of appreciation accorded to a State's protection of the unborn necessarily translates into a margin of appreciation for that State as to how it balances the conflicting rights of the mother).

[12] Para mayor análisis ver la resolución completa, así como el voto disidente del Juez Eduardo Vio Grossi, se puede consultar en: http://www.corteidh.or.cr/docs/casos/articulos/seriec_257_esp.pdf, 12-23-2015.

[13] Párr. 264.

[14] Párr. 223.

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[25] Mencionamos, aquí a pie de página, otras dos definiciones. La segunda edición de *Embriología médica* de Langman, de 1969, año de la Convención Americana: “El desarrollo de un individuo comienza con la fecundación, fenómeno por virtud del cual, dos células muy especializadas, el espermatozoide del varón y el ovocito de la mujer se unen y dan origen a un nuevo organismo, el cigoto”. Y la definición de Healy Edwin, F. 1959. Ética Médica. Concepción: “…tan pronto como las células masculinas y femeninas se unen vitalmente, tenemos presente un ser humano”.

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[49] Viabilidad es la cualidad de viable (que tiene probabilidades de llevarse a cabo o de concretarse gracias a sus circunstancias o características). El concepto también hace referencia a la condición del camino donde se puede transitar. Lee todo en: Definición de viabilidads-Qué es, Significado y Concepto http://definicion.de/viabilidad/#ixzz4K3j3tQ83

[50] Cfr. LILEY, A.W., Intrauterine transfusión of foetus in hemolytic disease. Br Med J., 1963; 5365: 1107-1109.

[51] Cfr. SCRIMGEOUR, J.B. *Other techniques for antenatal diagnosis*, EMBERRY, H.E.H (ed.), Antenatal diagnosis of genetic disease, N.Y. 1973, pp. 40-57.

[52] Cfr. HARRISON, M.R., GOLBUS, M.S., FILLY, R.A., *The unborn patient. Prenatal diagnosis and treatment*, GRUNE & STRATTON, Orlando, Florida, 1984, p. 440.

[53] Se puede consultar en: www.ifmss.org, 13-11-2016.

[54] Jama, Aug 14, 1981; 246(7): pp. 772-773.

[55] HARRISON y compañeros definen los riesgos y beneficios del diagnóstico y tratamiento fetal. Lo que se pretende es corregir o, al menos, mejorar una malformación.

[56] Cfr. PRINGLE, K.C., *Fetal surgery*: it has a past, has it a future: Fetal Ther. 1986, 1: 23-31.

[57] Ídem.

[58] Valor que se precisará más adelante.

[59] …el feto sufre de un deterioro fatal.

[60] …así como disfrutar de una vida digna.

[61] CRAIG, GRACE. *Desarrollo psicológico*. Prentice may. México. Séptima edición 2000, p.175.

[62] MORGAN, T. *Turner syndrome:* diagnosis and management. Am Fam Physician 76, 2007, pp. 405-410.

[63] Se puede consultar en: https://medlineplus.gov/spanish/ency/article/000382.htm, ver también: BACINO, C.A. Cytogenetics. In: KLIEGMAN, R.M, STANTON, B.F., S.T. GEME, J. III, SCHOR N, BEHRMAN, R.E., eds. Nelson Textbook of Pediatrics. 19th ed. Philadelphia, PA: Elsevier Saunders; 2011: chap 76, American Association for Klinefelter Syndrome Information and Support (AAKSIS): www.aaksis.org. National Institute of Health, National Human Genome Research Institute: www.genome.gov/19519068, consulta: 12-12-2016.

[64] Se puede consultar en: http://www.zonapediatrica.com/www.sindromedeklinefelter.es, consulta:12-12-2016.

[65] OHCHR, UNFPA, UNICEF, UN Women and WHO, *Preventing gender-biased sex selection*. An interagency statement, Ginebra, 2011.

[66] "17. The Committee takes note of Act 2/2010 of 3 March 2010 on sexual and reproductive health, which decriminalizes voluntary termination of pregnancy, allows pregnancy to be terminated up to 14 weeks and includes two specific cases in

which the time limits for abortion are extended if the foetus has a disability: until 22 weeks of gestation, provided there is «a risk of serious anomalies in the foetus", and beyond week 22 when, inter alia, "an extremely serious and incurable illness is detected in the foetus". The Committee also notes the explanations provided by the State party for maintaining this distinction. 18. The Committee recommends that the State party abolish the distinction made in Act 2/2010 in the period allowed under law within which a pregnancy can be terminated based solely on disability». Committee on the Rights of Persons with Disabilities. Sixth session, 19-23 September 2011: Consideration of reports submitted by States parties under article 35 of the Convention.

[67] Embryo donation Ivf Australia 2013.

[68] Goedeke S, Payne, D. Embryo donation in New Zealand: a pilot study Human Reprod 24, 2009, pp. 1939-1945

[69] Martos, C. Se adopta embrión, elmundo.es, se puede consultar en: http://www.elmundo.es/elmundosalud/2011/01/21/mujer/1295622563.html consulta:24-01-2014.

[70] Nightlight Christian Adoptions Snowflakes embryo adoption program. Frecuently asked questions by adopting families.

[71] Presidenza del Consiglio dei Ministri. Comitato Nazionale per la Bioetica. L' adozione per la nascita (Apn) degli embrioni crioconservati e residuali derivanti da procreazione medicalmente assistita (P.M.A). consulta: 18-11-2005

[72] The Ethics Committee of the American Society for Reproductive Medicine. American Society for Reproductive Medicine. Defining embryo donation. Fertil Steril; 92, 2009, pp. 1818-1819.

[73] National Institutes of Health. Report of the Human Embryo Research Panel. National Institutes of Health, 1994. New York State Department of Health. Task Force on Life and the Law. Assisted reproductive technologies, analysis and recommendations for public policy. New York: New York State, 1998.

[74] Pascual, F. *En España: mayoría de embriones de fecundación in vitro terminan destruidos*, Ideas Claras. 15-12-2011.

[75] Entre otros, Peter Singer, J. Harris, Engelhardt, Joseph Fletcher, Hoerster, etc.

[76] Caso Artavia Murillo y otros vs Costa Rica, parr. 187.

[77] Entre otros el Dr. Juan Ramos de la Cadena.

[78] Ibidem p.256.

[79] Ibidem p.43.

[80] Tapia, R., *La formación de la persona durante el desarrollo intrauterino, desde el punto de vista de la neurología*, s/f, s/e, publicado en www.colbio.org.mx Este texto se encuentra de la exposición que el propio Ricardo Tapia realizó para el Seminario de bioética organizado por la Scjn, el día 4 de diciembre de 2007, y Valdés, M., *El problema del aborto: tres enfoques*, en Vázquez, R. (comp.), Bioética y derecho. Fundamentos y problemas actuales, Fce, México, 2004, p. 136.

[81] Jouve De La Barreda, Nicolás, *Entidad del embrión Humano. Una explicación genética del desarrollo embrionario y la macro evolución*, se puede consultar en:

http://www.bioeticaweb.com/content/view/4515/782/lang,es/, consulta: 26-11-2007.

[82] Spaemann Robert, *No existe el derecho a un hijo sano*, entrevista realizada por S. Kummer, publicada en su versión castellana en Cuadernos de Bioética, vol xiv, nn. 51-52 (2ª-3ª), 2003, pp. 287-290.

[83] Bioética, El ser humano no puede ser tratado como una cosa, se puede consultar en: http://www.ewtn.com/vnews/getstory.asp?number=85702, consulta: 02-02-08.

[84] Cfr. Spaemann Robert, *¿Son todos los hombres personas?*, Artículo publicado en la revista Communio, 1990, pp. 108-114 La traducción castellana se publicó en cuadernos de Bioética, viii: 31, 1997. pp. 1027-1033.

[85] Cfr. George, Robert P., y Tollesen, Christopher, "Embrión. Una defensa por la vida humana". Madrid, España Rialp S.A., 2012: p. 15.

[86] Cfr. Guerra López, Rodrigo, *Bioética y norma personalista de la acción*. Elementos para una fundamentación personalista de la bioética, en Tomás y Garrido, Gloria Mariá, la bioética: un compromiso existencial y científico, fundamentación y reflexiones, textos de bioética, Universidad Católica san Antonio por Quaderna editorial, España, 2005, p. 80 y ss.

[87] Cfr. Kant, I, *Fundamentación para una metafísica de las costumbres*, Trad. Cast. R.R. Aramayo, Alianza, Madrid, 2002.

[88] Consejo de Europa, Recomendación 1046 sobre el uso de los embriones y fetos humanos con fines diagnósticos, terapéuticos, científicos, industriales y comerciales, 38ª Sesión Ordinaria, 1986, n.10.

[89] Rae, Se puede consultar *en: http://buscon.rae.es/draeI/, 12-01-2012.*

[90] vol. v, Oxford 1978.

[91] Según el "Dictionnaire de l'Académie Française", quiere decir: "Qui par sa nature est joint inséparablement à un sujet".

[92] Sentencia en el asunto C-34/10 Oliver Brüstle / Greenpeace eV, Se puede consultar en: http://curia.europa.eu/juris/liste.jsf?language=es&jur=C,T,F&num=34/10&td=ALL., 29-11-2015.

[93] M. Kloe P.F. er, *grundrechtstatbestand und grundrechtsschranken in der rechtsprechung der bundesverfassungsgerichts-dargestellt am beispiel der Menschenwürde, en Festgabe für das Bundesverfassungsgericht*, vol. ii, 1976, p. 412.

[94] Peris, Manuel. Juez, Estado y Derechos Humanos. Editorial Fernando Torres. Valencia 1976.

[95] Gómez Máximo, Pacheco. El concepto de derechos fundamentales de la persona humana, en Liberamicorum, Fix-Zamudio, Héctor, Volumen i Primera Edición: Corte Interamericana de Derechos Humanos, 1998.

[96] Ibidem.

[97] Caso Myrna Mack Chang, Sentencia de 25 de noviembre de 2003, Serie C N° 101, párr. 152; Caso Juan Humberto Sánchez, Sentencia de 7 de junio de 2003, Serie C N° 99, párr.110; Caso 19 Comerciantes, Sentencia de 5 de julio de 2004, Serie C N° 109, párrs. 152 y 153; Caso de la Masacre de Pueblo Bello, Sentencia

de 31 de enero de 2006, Serie C N° 140; Caso Comunidad Indígena Sawhoyamaxa, sentencia de 29 de marzo de 2006, Serie C N° 146, párr. 150; Caso Baldeón García, Sentencia de 6 de abril de 2006, Serie C N° 147, párr. 82; Caso de las Masacres de Ituango, Sentencia de 1 de julio de 2006, Serie C N° 148, párr. 128; Caso Ximenenes Lopes, Sentencia de 4 de julio de 2006, Serie C N° 149, párr. 124; Caso Montero Aranguren y otros (Retén de Catia), Sentencia de 5 de julio de 2006, Serie C N° 150, párr. 63; Caso Albán Cornejo y otros, Sentencia de 22 de noviembre de 2007, Serie C N° 171, parr. 117.

[98] Castillo González y Otros Vs. Venezuela y Masacres de El Mozote y Lugares Aledaños Vs. El Salvador, ambas sentencias de octubre de 2012.

[99] Caso del Penal Miguel Castro Castro Vs. Perú, Fondo, Reparaciones y Costas, Sentencia de 25 de noviembre de 2006, párr.292.

[100] Caso de los Hermanos Gómez Paquiyauri Vs. Perú, Fondo, Reparaciones y Costas, Sentencia de 8 de julio de 2004, párr. 67, x).

[101] En esta línea de interpretación expansiva, la Corte IDH ha entendido que el artículo 29.b de la CADH expresamente obliga a un examen judicial que incorpore, al momento de determinar el alcance de los derechos, todas aquellas normas jurídicas, tanto nacionales como internacionales, que hayan reconocido un derecho de forma más extensa. En este sentido, la Corte IDH se ha referido constantemente a diversos instrumentos internacionales, ya sean regionales o universales, con el fin de dar sentido a los derechos reconocidos en la CADH, pero atendiendo a las circunstancias específicas del caso. Véanse, por ejemplo, Corte IDH, Caso Las Palmeras vs. Colombia (Fondo), Sentencia del 6 de diciembre de 2001, serie C, núm. 90; Corte IDH, Caso Bámaca Velásquez vs. Guatemala (Fondo), Sentencia del 25 de noviembre de 2000, serie C, núm. 70 (alcance del derecho a la vida en situaciones de conflictos armados no internacionales); Corte IDH, Caso de las Masacres de Ituango vs. Colombia (Excepción Preliminar, Fondo, Reparaciones y Costas), Sentencia del 1 de julio de 2006, serie C, núm. 148 (prohibición del trabajo forzado u obligatorio); Corte IDH, Caso Herrera Ulloa vs. Costa Rica (Excepciones Preliminares, Fondo, Reparaciones y Costas), Sentencia del 2 de julio de 2004, serie C, núm. 107 (relación entre la libertad de expresión y la sociedades democráticas); Corte IDH, Caso de los “Niños de la Calle” (Villagrán Morales y otros) vs. Guatemala (Fondo), Sentencia del 19 de noviembre de 1999, serie C, núm. 63 (derechos específicos de los niños y niñas, menores de 18 años); y Corte IDH, Caso Comunidad Indígena Yakye Axa vs. Paraguay (Fondo, Reparaciones y Costas), Sentencia del 17 de junio de 2005, serie C, núm. 125 (derecho a la propiedad comunal de los pueblos indígenas), entre otros.

[102] Véanse, por ejemplo, Corte IDH, Caso Las Palmeras vs. Colombia (Fondo), doc. cit., y Corte IDH, Caso Radilla Pacheco vs. México (Excepciones Preliminares, Fondo, Reparaciones y Costas), Sentencia del 23 de noviembre de 2009, serie C, núm. 209 (interpretación restringida del alcance del fuero militar, entendiendo éste como una limitación a ciertos derechos de la víctima y al principio de unidad jurisdiccional); Corte IDH, Caso Boyce y otros vs. Barbados (Excepción Preli-

minar, Fondo, Reparaciones y Costas), Sentencia del 20 de noviembre de 2007, serie C, núm. 169; Corte IDH, Caso Benjamin y otros vs. Trinidad y Tobago (Excepciones Preliminares), Sentencia del 1 de septiembre de 2001, serie C, núm. 81; Corte IH, Caso Constantine y otros vs. Trinidad y Tobago (Excepciones Preliminares), Sentencia del 1 de septiembre de 2001, serie C, núm. 82; y «Voto razonado del juez Sergio García Ramírez en el caso Raxcaco Reyes vs. Guatemala. Sentencia del 15 de septiembre de 2005», en Corte IDH, Caso Raxcacó Reyes vs. Guatemala (Fondo, Reparaciones y Costas), Sentencia del 15 de septiembre de 2005, serie C, núm. 133, (interpretación restringida de las condiciones bajo las cuales se puede imponer la pena de muerte), entre otras decisiones.

[103] Véanse, por ejemplo, Corte IDH, Caso Comunidad Indígena Sawhoyamaxa vs. Paraguay (Fondo, Reparaciones y Costas), Sentencia del 29 de marzo de 2006, serie C, núm. 146 (si por una actuación negligente del Estado no se puede establecer la fecha de la muerte de las presuntas víctimas, para efectos de determinar la competencia temporal de la Corte IDH, ésta podrá conocer de las violaciones, en aplicación "procesal" del principio pro persona); y Corte IDH, Caso de la Masacre de Pueblo Bello vs. Colombia (Fondo, Reparaciones y Costas), Sentencia del 31 de enero de 2006, serie C, núm. 140, y Corte IDH, Caso Trabajadores Cesados del Congreso (Aguado Alfaro y otros) vs. Perú (Excepciones Preliminares, Fondo, Reparaciones y Costas), Sentencia del 24 de noviembre de 2006, serie C, núm. 158 (el no haber otorgado un poder formal de representación ante la Corte IDH no es un argumento para excluir a una persona como víctima potencial de un caso).

[104] Bioética y los Derechos del Niño, 31 C/12 18 de julio de 2001 Original: Francés, Conferencia General 31ª reunión, París 2001, celebrado en Mónaco del 28 al 30 de abril de 2000, Anexo II, p. 2.

[105] Párr.66.

[106] Entre otros en la Declaración de Asilomar, la Nota N° 12/2000 del Parlamento Europeo y la declaración de Lowell.

[107] Lista de organizaciones que firman la Carta Abierta: Acciónn Ecologica (Ecuador) -www.accionecologica.org- Elizabeth Bravo California for GE Free Agriculture - www.calgefree.org - Becky Tarbotton Centro Ecológico (Brazil) - Maria Jose Guazzelli Clean Production Action - www.cleanproduction.org - Beverley Thorpe Cornerhouse UK - www.thecornerhouse.org.uk - Nick Hildyard Corporate Europe Observatory - www.corporateeurope.org - Nina Holland Corporate Watch (UK) - www.corporatewatch.org - Olaf Bayer EcoNexus - www.econexus.info - Ricarda Steinbrecher Ecoropa - Christine Von Weisczacker Edmonds Institute - www.edmonds-institute.org - Beth Burrows ETC Group - www.etcgroup.org - Jim Thomas Farmers Link - www.farmerslink.org.uk - Hetty Selwyn Friends of the Earth International - www.foe.org - Juan Lopez, Lisa Archer (USA), Georgia Miller (Australia) Foundation on Future Farming (Germany) - http://www.zs-l.de - Benedikt Haerlin Fondation Sciences Citoyennes (France) - www.sciencescito yennes.org - Claudia Neubauer Gaia Foundation - www.gaiafoundation.org - Teresa Anderson GeneEthics Network (Australia) - www.geneethics.org - Bob Phelps

Genewatch (UK) -www.genewatch.org - Sue Mayer GRAIN - www.grain.org - Henk Hobbellink Greenpeace International - www.greenpeace.org - Doreen Stabinsky Henry Doubleday Research Association (UK) - www.gardenorganic.org.uk - Julia Wright Indigenous People's Biodiversity Network - Alejandro Argumedo International Center for Technology Assessment - www.icta.org - Jaydee Hanson International Network of Engineers and Scientists for Global Responsibility - www.inesglobal.com - Alexis Vlandas Institute for Social Ecology - www.socialecology.org - Brian Tokar International Center for Bioethics, Culture and Disability - www.bioethicsanddisability.org - Gregor Wolbring International Union of Food and Agricultural Workers - www.iuf.org - Peter Rossman Lok Sanjh Foundation (Pakistan) - www.loksanjh.org - Shahid Zia National Farmers Union (Canada) - www.nfu.ca - Terry Boehm Oakland Institute - www.oaklandinstitute.org - Anuradha Mittal Polaris Institute - www.polarisinstitute.org - Tony Clarke Pakistan Dehqan Assembly - contact via Lok Sanjh - see above. Practical Action - www.practicalaction.org - Patrick Mulvany Quechua Ayamara Association for Sustainable Livelihoods, (Peru) - www.andes.org.pe - andes@andes.org.pe Research Foundation for Science, Technology and Ecology (India) - www.navdanya.org - Vandana Shiva Soil Association - www.soilassociation.org - Gundula Azeez Sunshine Project - www.sunshine-project.org - Edward Hammond Third World Network - www.twnside.org.sg - Lim Li Ching.

[108] Corte IDH, Condición Jurídica y Derechos humanos del Niño, Opinión Consultiva OC-17/02, del 29 de agosto de 2002, Serie A No. 17, párr. 54.

[109] Emitida durante el periodo de sesiones de dos mil y aprobada el once de mayo de dicho año.

[110] Dentro de la locución "nadie" se comprende todo ser humano, lo que supone que ninguna vida humana puede ser privada arbitrariamente. La prohibición de no imponer la pena de muerte a las mujeres embarazadas revela la clara intención de proteger al *nasciturius* pues el compromiso de no aplicar dicha pena no se sustenta en su calidad de mujer como tal, sino en su estado de gravidez, de lo que deriva que una vez concluido este estado, ya no subsistiría la prohibición.

[111] Cfr. Rodolfo Carlos, Barra. *La Protección Constitucional del Derecho a la Vida*, Editorial Abeledo-Perrot, Buenos Aires, Argentina, 1996, pp. 41 y 42.

[112] La Declaración de Viena, adoptado por la segunda Conferencia Mundial sobre Derechos Humanos, celebrada en Viena en 1993: "Todos los derechos humanos son universales, indivisibles e interdependientes y están relacionados entre sí. La comunidad debe tratar los derechos humanos en forma global de manera justa y equitativa, en pie de igualdad y dándoles a todos la misma importancia." (párr. 5).

[113] Comité de Derechos Humanos, Observación General No. 6, párr. 1 (1982), mismo que se repite en la Observación general N°14 Párr. 1 (1984).

[114] Comité de Derechos Humanos, caso A.R.J. c. Australia, párr.6.8 (1997); G. T. c. Australia, párr. 8.1 (1998).

[115] Corte Interamericana, Caso de la Masacre de Pueblo Bello c. Colombia, párr. 120 y Caso del Penal Miguel Castro Castro c. Perú, párr. 237, entre otras.

[116] Corte Interamericana de Derechos Humanos, Opinión Consultiva OC-16/99, párr. 135.

[117] Corte Interamericana, Caso Comunidad indígena Yakye Axa c. Paraguay, párr. 161.

[118] Caso de los Niños de la Calle (Villagrán Morales y Otros), Sentencia de 19 de noviembre de 1999, Serie C N° 63, párr. 144.

[119] Caso Familia Barrios Vs. Venezuela. Fondo, Reparaciones y Costas. Sentencia de 24 de noviembre de 2011. Serie C No. 237, párr. 48.

[120] Corte Interamericana, Caso comunidad Sawhoyamaxa c. Paraguay, párr. 150 y Masacres de Ituango c. Colombia, párr. 128, entre otras.

[121] Corte Interamericana, Caso Masacres de Ituango c. Colombia, párr. 129 y Caso Zambrano Vélez y otros c. Ecuador, párr. 79.

[122] CIDH, caso Remolcador 13 de marzo c. Cuba, párr. 79 (1996).

[123] CIDH, caso Remolcadora 13 de marzo, párr. 79. Ver también Sequieras Mangas c. Nicaragua, párr. 145 (1997). La CIDH hace una exégesis de la relación y las diferencias entre los conceptos de Derecho Consuetudinario y de *jus cogens* en los párrafos 43 a 50 de su decisión de en el caso Domínguez c. Estados Unidos (2002).

[124] CIDH, caso Edwards y otros c. Bahamas, párr. 109 (2001).

[125] Diccionario de la Real Academia de la Lengua, se puede ver: http://dle.rae.es/?id=3QAUXFg

[126] Artículo 7 Nadie será sometido a torturas ni a penas o tratos crueles, inhumanos o degradantes. En particular, nadie será sometido sin su libre consentimiento a experimentos médicos o científicos.

[127] MILLER, PAUL STEVEN Y REBECCA LEAH, LEVINE. 2013. Avoiding genetic genocide: understanding good intentions and eugenics in the complex dialogue between the medical and disability communities. *Genet Med*. 15(2): 95-102.

[128] NIZAR, SMITHA. 2011. Impact of UNCRPD on the status of persons with disabilities. *Indian Journal of Medical Ethics*. VIII (4): 223-229.

[129] ASCH, ADRIANNE AND DORIT BAVERLY. 2012. Disability and Genetics: A Disability Critique of Pre-natal Testing and Pre-implantation Genetic Diagnosis (PGD). En: eLS John Wiley & Sons, Ltd: Chichester.

[130] FERRAJOLI, LUIGI, *Derecho y garantías. La ley del más débil*, Trotta, Madrid 5ed, 74-76.

[131] Cfr. SADLER, T.W., LANGMAN, *embriología médica: con orientación clínica*, Médica Panamericana, Buenos Aires, 2004, p 3 y HIB, J., *Embriología Médica*, Interemericana-Mc Graw-Hill, México, 1994, p. 8.

[132] KESSLLER S., "Soloveitchik and Levinas: pathways to the other", en *Judaism: A Quarterly Journal of Jewish Life and Thought*, 10/4 (2002), 444: «In the face-to-face encounter we become aware of the Other's vulnerability which calls to us not to harm him or her. *Thou shalt not kill* is the primary command and killing or violence encompass any attempt to deny the reality or separateness of the other, to reduce the other to a concept, an idea, an *It* or to absorb him or her into the self.

In the face of the other, we are “summoned» to responsibility and in our response, «*Me voice; Here I am; Hineni*”, we take on ethical responsibility».

[133] Citado en el Informe del Comité de Bioética de España sobre el Anteproyecto de Ley Orgánica para la Protección de la Vida del Concebido y de los Derechos de la Mujer Embarazada, ver file:///G:/Informe%20Anteproyecto%20LO%20Proteccion%20Concebido.pdf

[134] Consejo Económico y Social Documentos Oficiales, 2014 Suplemento núm. 5, Comisión de Población y Desarrollo, Informe sobre el 47º período de sesiones (26 de abril de 2013 y 7 a 11 de abril de 2014) E/2014/25-E/CN.9/2014/7, se puede consultar en: http://www.unfpa.org/sites/default/files/event-pdf/N1431211_SP.pdf

[135] Diccionario de la Lengua Española, RAE, vigésima edición, 2014, p. 1289.

[136] KOCH, E, ARACENA, P., GATICA, S., BRAVO, M., HUERTA-ZEPEDA A., CALHOUN, B.C. Fundamental discrepancies in abortion estimates and abortion-related mortality: A reevaluation of recent studies in Mexico with special reference to the International Classification of Diseases. Int J Womens Health. 2012;4:613-23.

[137] KOCH, E., CHIREAU, M., PLIEGO, F., STANFORD, J., HADDAD, S., ET AL. Abortion legislation, maternal healthcare, fertility, female literacy, sanitation, violence against women and maternal deaths: a natural experiment in 32 Mexican states BMJ Open 2015;5:e006013. doi: 10.1136/bmjopen-2014-006013

[138] Idem.

[139] KOCH, E., THORP, J., BRAVO, M., GATICA, S., ROMERO, C.X. AGUILERA, H., AHLERS, I. Women’s education level, maternal health facilities, abortion legislation and maternal deaths: a natural experiment in Chile from 1957 to 2007. *PLoS One* 2012;7(5):e36613.

[140] Ídem.

[141] En el experimento natural chileno se avalúo una serie temporal de 50 años, entre 1957 y 2007, analizando el efecto de la derogación del aborto terapéutico en 1989. La tendencia continuó a la baja, sin detectarse cambios significativos asociados al cambio legislativo. El progreso en el nivel de escolaridad de las mujeres, la tasa de cobertura de atención profesional del parto, la reducción tasa de fecundidad, la edad de la mujer para el primer hijo, la cobertura de agua potable y alcantarillado fueron las variables que explicaron la tendencia secular decreciente.

[142] Ídem

[143] Ídem.

[144] FERNÁNDEZ BEITES, PILAR. *Sustantividad humana: embrión y actividad pasiva de inteligencia,* en: *Filosofía práctica y persona humana, V.V.*A.A. coord. Murillo, Ildefonso, Universidad Pontificia de Salamanca, Servicio de Publicaciones 2004.

[145] HAN BYUNG-CHUL, la sociedad del cansancio, Herder, 2012.

[146] BAUDRILLARD, J., La transparencia del mal, Ensayo sobre los fenómenos extremos, Barcelona, Anagrama, 1991, p. 82.

[147] Violencia de la imagen. Violencia contra la imagen, en la agonía del poder, Madrid, circulo de bellas artes, 2006, pp. 45-47.

[148] NIETZSCHE, F., Así hablo Zaratustra, Madrid, Alianza, 2011, 1972, p. 40.

[149] Ver: http://www.who.int/features/factfiles/mental_health/es/, también en: Eutanasia sí o no, se puede consultar en: http://www.formacionsinbarreras.com/weblog/modules.php?name=News&file=article&sid=171

[150] Adoptada por la 39ª Asamblea de la Asociación Médica Mundial-AMM- en Madrid, España, octubre 1987, reafirmada por la 170ª Sesión en Divonne-Les-Bains, Francia, mayo 2005.

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[160] Los valores son cualidades adherida a un objeto o bien, de existencia virtual, no concreta, absolutos y universales. La vida es el máximo valor porque de ella emanan todos los demás valores, sin vida, no hay base para los otros. Ver FRONDIZI, RISIERI (1995) Introducción a la axiología. México, Fondo de Cultura Económica, páginas 11-23.

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Aspectos éticos del consentimiento informado en la investigación translacional/clínica y sobre el sesgo o prejuicio en los ensayos clínicos

Ethical Issues Concerning Informed Consent in Translational/Clinical Research and Vaccination Bias and Informed Consent

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Resumen

Mejorar la educación en salud de los pacientes en relación con las prácticas médicas y la investigación es esencial para defender el principio del respeto a la autonomía, es decir, respetar la capacidad del paciente para tomar decisiones autónomas con respecto a las intervenciones médicas o a la participación en la investigación que refleje las creencias y valores del paciente. Este artículo considera los desafíos del consentimiento informado (es decir, brechas éticas, barreras y necesidades prioritarias) que son

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Este ensayo ha sido elaborado como parte del proyecto i-CONSENT que ha recibido fondos del programa de investigación e innovación Horizonte 2020 de la Unión Europea mediante acuerdo No 741856: www.i-consentproject.eu
Recibido el 06 de marzo de 2019. Aceptado el 08 de marzo de 2019.

exclusivos de ciertos grupos vulnerables, como preadolescentes, adolescentes y mujeres embarazadas, con un énfasis específico en cómo deben tomarse en cuenta las variables neurobioéticas, multiculturales e interreligiosas para valorar la idoneidad de los documentos actuales que se basan en la noción de consentimiento informado. Al explorar cómo hemos de mejorar el proceso de obtención del consentimiento informado, este artículo presta especial atención a la relevancia del sesgo y la privacidad en el debate, sugiriendo nuevas formas de intervención para reducir los efectos del sesgo o prejuicio implícito.

Palabras clave: Autonomía, Sesgo, Prejuicio, Bioética, Competencia, Consentimiento informado, Vacunación

Introducción

El proceso de consentimiento informado requiere de cuatro características para ser válido: voluntariedad, divulgación, comprensión y capacidad. Cuando falta uno de estos elementos, el consentimiento informado puede verse comprometido.[1]

Voluntariedad significa que los pacientes deben tomar la decisión de participar sin ser influidos o coaccionados y comprender que no tienen la obligación de participar y, si lo hacen, tienen derecho a retirarse en cualquier momento.[2] [3]

Divulgación significa dar a los sujetos toda la información relevante y correcta sobre la investigación, incluidos los riesgos, los beneficios potenciales, su naturaleza y otras alternativas terapéuticas. De acuerdo con las consideraciones éticas del Informe Belmont, los siguientes principios son específicamente relevantes en relación con los problemas existentes al revelar la información en el proceso de obtención del consentimiento informado. El principio de autonomía y la de decir la verdad, implica proporcionar siempre la información completa a cada paciente. Sin embargo, basándose en el principio de beneficencia y el principio de no maleficencia, generalmente la aproximación correcta es una divulgación parcial. El principio de justicia no será considerado en el análisis de la divulgación debido a su menor relevancia en relación con el tema.[4] [5] La comprensión implica que los participantes tengan la capacidad de comprender la información y entender su relevancia en sus vidas personales en condiciones razonadas. En otras palabras, se debe proporcionar información apropiada, precisa y relevante en un lenguaje y formato que los pacientes entiendan completamente. [6] [7] [8] La capacidad en cualquier situación clínica significa ser competencia para tomar decisiones autónomas y participar en un ensayo clínico con deliberaciones razonadas, comparando los riesgos y beneficios del procedimiento. Un paciente debe tener la capacidad de autodeterminación para reflexionar, considerar y decidir acerca de su participación en un ensayo clínico.[9] [10] La capacidad también se puede considerar como una escala móvil, donde no todas las decisiones necesitan el mismo nivel de capacidad. De esta manera, un paciente podría tener la capacidad de tomar una decisión pero no otra. A medida que aumenta la importancia de la decisión, y la información proporcionada es más específica y precisa, el umbral para considerar que un paciente es capaz también es más alto. Por ejemplo, una decisión de vida o muerte con información clínica y técnica tendría un alto umbral de capacidad y el paciente tendría que mostrar el nivel requerido de capacidad para razonar el proceso de toma de decisiones.[11],[12] En la siguiente sección, se explorará con mayor detalle el papel que los investigadores pueden tener (con su sesgo) en la obtención del consentimiento informado.

¿Qué es el sesgo o prejuicio?

Un paciente debería recibir atención diferenciada en base a su grupo étnico, género o cualquier otro factor específico. Aún así, hay sesgos o prejuicios existentes entre los profesionales de la salud que contribuyen a crear disparidades.[13] [14] El prejuicio, en este contexto, es referido por los psicólogos como «la evaluación negativa de un grupo y sus miembros en relación con otro».[15]

Un estereotipo es «una estructura cognitiva que contiene las creencias, conocimientos y expectativas del perceptor sobre un grupo humano».[16] La razón por la cual las personas tienen estereotipos es porque es una forma de simplificar el procesamiento y almacenamiento de información de una manera más eficiente en términos de energía mental y tiempo. Se ha probado que estereotipar repetidamente conduce a un sistema psicológico donde la conciencia desaparece y se vuelve implícita incluso cuando una persona está educada en la diversidad multicultural y no tiene la intención negativa consciente de usar sus estereotipos.[17]

Hay dos tipos de sesgo o prejuicio: explícito e implícito. El sesgo explícito es aquel del cual la persona tiene conciencia y se asocia con conductas deliberativas (por ejemplo, verbales). En los últimos 50 años, el sesgo explícito en relación al origen étnico o las creencias religiosas ha disminuido significativamente, siendo hoy en día inaceptable dentro de la sociedad en general.[18] Sin embargo, el sesgo implícito es el que hace que una persona actúe de manera no intencional e inconsciente, y realice asociaciones y juicios negativos inconscientemente. Este tipo de sesgo implícito es persistente y común en la sociedad y es difícil de controlar. El sesgo implícito se asocia normalmente con el comportamiento espontáneo no verbal, como el contacto visual repetido, estar alejado de una persona que no pertenece al mismo grupo étnico que el tuyo, la expresión facial, etc. Por ejemplo, una persona podría pensar que él o ella no es racista, pero luego, involuntariamente, tiene actitudes que lo hacen actuar de una manera sesgada. Este comportamiento no consciente puede influir en la toma de decisiones, las percepciones del paciente y de los profesionales de la salud y, por lo tanto, en la calidad de la atención. Las actitudes raciales implícitas han sido consideradas como una de las razones que pueden explicar por qué los médicos brindan atención de menor calidad a pacientes de diferentes orígenes étnicos, incluso cuando tienen la intención de brindar la misma atención a todos.[19] [20] [21] [22] [23]

Reclutamiento de minorías

El reclutamiento en la investigación está influenciado por varios factores que deben identificarse para mejorar este proceso.[24] Cuando se habla de minorías, el reclutamiento para ensayos clínicos tiene aún más barreras y brechas que deben abordarse.[25] A los investigadores clínicos les ha resultado difícil inscribir a pacientes pertenecientes a minorías debido a una relación de desconfianza, diferencias de idioma, valores culturales y acceso limitado a sus poblaciones.[26] De esta manera, un estudio que entrevistó y buscó experiencias y perspectivas de investigadores principales, personal de investigación, médicos y líderes de centros de cancerología mostró que las minorías a menudo se enfrentan a barreras de múltiples niveles que los excluyen de la posibilidad de participar en ensayos clínicos. La discordancia lingüística fue una de las barreras en las que los investigadores sugirieron que el tiempo y el esfuerzo requeridos por los traductores podrían disuadir a otros de ofrecer el ensayo a estos pacientes.[27]

Un estudio cualitativo realizado en Londres, donde se entrevistó a tres equipos de investigación clínica, mostró que había cuatro temas relevantes para el reclutamiento: la infraestructura, la naturaleza de la investigación, la características del reclutador y las características de los participantes. Centrándose en las características del reclutador, se observó que ninguno de los reclutadores había recibido capacitación específica en reclutamiento. Hubo debate sobre si esta capacitación podría afectar o no las habilidades del reclutador o podría ser útil para mejorarlas. Al final, se concluyó que la personalidad de un individuo era crucial para reclutar en modo exitoso, lo que significa que es un aspecto difícil de enseñar. Esto sugiere nuevamente que existe un sesgo por parte del investigador que puede afectar el reclutamiento y, en consecuencia, el proceso de obtención del consentimiento informado, ya que cada persona es diferente y, por lo tanto, puede influir en el hecho de ofrecer o no la participación en un ensayo clínico a un sujeto potencial. Además, normalmente no se emplean estrategias específicas para el reclutamiento de pacientes de diferentes etnias y orígenes sociodemográficos debido a la creencia de que los reclutadores invitan a participar a todos los pacientes elegibles, a pesar de sus orígenes. Sin embargo, la verdad es que los reclutadores tienden a estereotipar a los posibles participantes en función de sus experiencias previas y optan por no elegir a personas que de otra manera serían elegibles. [28]

Un grupo de investigación del Reino Unido (*Centre for Population Health Sciences* de la Universidad de Edimburgo; el *National Heart & Lung Institute* y la *Division of Epidemiology of the Imperial College London*; también el *Medical Research Council* (MRC)- *Asthma UK Centre for Allergic Mechanisms in Asthma of the Barts* y la *London School of Medicine and Dentistry*) llevó a cabo un estudio de tipo cualitativo en el que se realiza una comparación entre Estados Unidos y el Reino Unido en términos de multiculturalismo y actitudes multiétnicas al reclutar minorías para la investigación. Este estudio se considera particularmente relevante en este informe, ya que los Estados Unidos es un país de referencia con grandes diferencias multiétnicas y multiculturales en la población y una gran experiencia en la realización de ensayos clínicos. El estudio consistió en entrevistas con 19 investigadores del Reino Unido y 17 de los Estados Unidos. Los resultados revelaron una gran brecha entre ambos países en términos de políticas, actitudes, prácticas y experiencias en relación con la inclusión de minorías étnicas en procesos de investigación. El estudio mostró pruebas de que investigadores del Reino Unido tenían muchos estereotipos y prejuicios que influían negativamente en el proceso de reclutamiento de minorías étnicas. Por ejemplo, un investigador presentó a las minorías étnicas como carentes de altruismo, afirmando que esta población estaba más centrada en sus familias que en la sociedad en general, y describía a las personas del sur de Asia como «un poco egoístas».[29] Esta brecha entre los EE. UU. Y el Reino Unido (hasta cierto punto asimilables con gran parte de Europa) podría explicarse por la presencia en los EE. UU. de las políticas del *National Institutes of Health* (NIH) en relación con el reclutamiento de mujeres y minorías en los ensayos clínicos, que responsabiliza a los investigadores de garantizar que las mujeres y los miembros de las minorías y sus subpoblaciones se incluyan en todas las investigaciones humanas, sin permitir que el costo sea una razón para excluirlos, e iniciar programas y apoyo para los esfuerzos de divulgación para reclutar a estos grupos. La ausencia de tal política en el Reino Unido, sumándose los prejuicios y estereotipos, contribuye a la subrepresentación de estos grupos en los ensayos clínicos y, por lo tanto, al sesgo o prejuicio de los investigadores existentes en el proceso de obtención del consentimiento informado.[30] Además, los médicos también pueden encontrar dificultades para comunicar la información a sus pacientes, porque les preocupa que la información pueda asustarlos en algunos casos. Por esta razón, la actitud del investigador puede llevar a un reclutamiento sesgado que selecciona a los pacientes considerados «más fáciles» para recibir la comunicación.[31]

Influencia del investigador

El proceso de toma de decisiones del paciente también puede ser influenciado consciente o inconscientemente por el investigador. De tal manera que varios estudios han demostrado que la influencia de los investigadores es una de las variables más determinantes en la participación de los pacientes en los ensayos clínicos. Los pacientes tienden a aceptar la participación cuando tienen una buena relación con el investigador y se establece una relación de confianza entre ellos. Sin embargo, cuando los pacientes no confían en su médico, o el médico incluso los desalienta, es más probable que rechacen la participación.[32] Así pues, también se influye en el consentimiento informado sugiriendo que los pacientes no están siendo informados objetivamente y que el investigador y otros factores externos influyen en su consentimiento. También hay otro tipo de sesgo, llamado sesgo de optimismo, que se ha observado tanto en pacientes como en investigadores. Este tipo de sesgo es más probable en los ensayos clínicos de fase I en los que los pacientes normalmente no tienen otra alternativa al tratamiento y aceptan participar en la investigación porque es su única opción. En este contexto, surgen problemas éticos sobre si estos pacientes están dando su consentimiento sin comprender realmente el propósito del ensayo o sin información suficiente para tomar una decisión de consentimiento informado. Por ejemplo, en los sujetos con cáncer de fase I, el sesgo de optimismo se encuentra comúnmente. Esperan tener posibilidades de obtener un alto beneficio médico. A veces, incluso los investigadores no son inmunes al sesgo de optimismo terapéutico. A pesar de sus predicciones de supervivencia, muestran un sesgo de optimismo cuando se trata de pacientes que conocen mejor o que han tratado durante más tiempo. Este sesgo de optimismo es uno de los más consistentes en psicología y sus consecuencias se muestran en pacientes dispuestos a participar en el ensayo clínico e investigadores dispuestos a proponerlo.[33]

Límites de la divulgación

Otro aspecto a considerar son los límites de divulgación en el consentimiento informado. Por ahora, solo se ha discutido el punto de vista en el que la opinión, perspectiva y características del investigador pueden influir en el proceso de toma de decisiones de un sujeto potencial. Sin embargo, otras opiniones y críticas afirman que, a menos que los sujetos sean informados de las características personales, puntos de vista y promotores de estos investigadores, su autonomía está siendo anulada, lo que significa que los sujetos podrían considerar la información sobre los investigadores importante para sus decisiones. Pero también está la cuestión de que no se respeta la privacidad del investigador y que no se discrimina en base a sus características.[34]

Hay diferencias en la forma en que las personas entienden, aceptan y reaccionan cuando se enfrentan a malas noticias, e incluso existen culturas en las que no se permite dar malas noticias, mientras que otros piensan que toda información es necesaria, etc. A causa de estas opiniones divergentes, la divulgación de información debe pensarse cuidadosamente y considerando estas preguntas: ¿Quién? ¿Dónde? ¿Qué? ¿Cómo?[35]

Con respecto a quién debe divulgar la información, el médico que mejor conoce al paciente debe hacerlo.[36] ¿Dónde? Siempre se debe revelar en una habitación privada y tranquila, no en mitad del pasillo o frente a otras personas.[37] ¿Qué? La información relevante y adecuada debe ser divulgada en cada caso, atendiendo a aquello que sea la mejor para el paciente.[38] ¿Cómo? La información siempre debe ser divulgada de manera sensible y empática, considerando también el lenguaje corporal, el comportamiento no verbal y las palabras usadas. Además, los pacientes deben tener su tiempo para procesar la información y disponer de una segunda visita si así lo desean.[39]

Sesgo étnico/racial implícito: un enfoque neurocientífico

Hemos visto en las secciones anteriores que tanto la neurociencia como el contexto cultural son variables importantes a tener en cuenta al evaluar el consentimiento informado, y esto también se aplica a lo que concierne al sesgo implícito. En general, los investigadores clínicos y los profesionales de la salud muestran respeto por otras culturas y etnias, pero cuando se aplican a situaciones reales e investigaciones clínicas, se identifican muchas lagunas.

Esto sugiere que existe un sesgo inconsciente y un estereotipo que conduce a dificultades en la comunicación, la inscripción y el proceso de consentimiento informado cuando otras culturas y poblaciones están involucradas.[40]

Se ha visto que cuando los profesionales de la salud tienen el tiempo adecuado para procesar la información, suficientes recursos cognitivos y la motivación necesaria para evitar sesgos y prejuicios, la atención que brindan es igual en diferentes pacientes y se ve influenciada por un sesgo implícito. Sin embargo, estas actitudes implícitas pueden influir en el comportamiento y la cognición cuando la capacidad del proceso cognitivo se ve alterada por factores como la ansiedad, el estrés, la enfermedad, la fatiga o la sobrecarga cognitiva. Además, en este contexto, cuando la capacidad cognitiva está demasiado cargada, es más probable que las personas estereotipen y se den a la categorización automática debido a que la memoria está sesgada hacia actitudes implícitas, difíciles de anular. Por esta razón, es importante tener esto en cuenta en contextos clínicos/médicos, donde es fácil encontrarse en situaciones con estrés, presión del tiempo y memoria de trabajo, que pueden llevar a una sobrecarga cognitiva y, por lo tanto, a una conducta sesgada.[41] [42]

Una gran cantidad de diferentes estudios realizados en diferentes países encontraron evidencia de la existencia de sesgo implícito entre los profesionales de la salud, utilizando diferentes métodos de prueba y estudiando diversas características sociodemográficas. Los resultados mostraron que cuanto mayor era el nivel de sesgo implícito, peor era la calidad de la atención. Existe evidencia clara de que existe una relación entre el sesgo implícito y los efectos negativos en la interacción con el paciente, pero, aunque esto no siempre significa un mal trato, la verdad es que una buena relación entre el paciente y el profesional de la salud es crucial para proporcionar una buena atención.[43] Otro estudio indicó que el sesgo racial implícito en favor de las personas blancas sobre personas de color mostró actitudes menos centradas en el paciente por parte de los clínicos, con un tono menos emocional y una comunicación negativa, que calificaron como deficiente el cuidado de la visita.[44]

De hecho, los resultados han demostrado que la mayoría de los prejuicios étnicos implícitos son favorables para personas blancas sobre personas de color, siendo estas actitudes diferentes entre los profesionales de la salud masculinos o femeninos, siendo más fuertes para en los varones, que tienen mayores preferencias por los blancos en lo que se refiere a actitudes raciales explícitas e implícitas.[45]

Pasos a seguir

El sesgo implícito se puede considerar como una asociación automática entre dos términos (señal y respuesta). Se ha demostrado que tratar de cambiar la asociación es más efectivo que tratar de cambiar la respuesta en sí misma, porque el sesgo implícito es difícil de controlar e incluso si los médicos están convencidos de querer reducir sus percepciones y sesgos implícitos, no se garantiza que los hayan borrado y no puedan volver a aparecer después de un tiempo. De esta manera, existen algunos casos en los que admirados afroamericanos se presentan a personas blancos y, posteriormente, se reduce el sesgo implícito. Esta técnica debe traducirse a contextos clínicos, pero sugiere una posible forma de abordar el sesgo.[46] [47]

Otra posible medida podría ser abordar la amenaza del estereotipo que tienen algunos pacientes, que se ha demostrado que puede alterar la comunicación entre el paciente y el investigador y, por lo tanto, aumentar la desconfianza. Son necesarias acciones que disminuyan las percepciones de amenaza del paciente. La autoafirmación es el proceso en el que se afirman los valores de la integridad personal, y a veces se utiliza en el sector educativo para disminuir problemas raciales. Por lo tanto, la autoafirmación podría ayudar a reducir el sesgo implícito y mejorar la relación paciente-investigador.[48]

Investigaciones emergentes han demostrado que la cognición explícita se puede utilizar para controlar y mitigar actitudes implícitas. Teniendo en cuenta esto, una de las estrategias sugeridas para los profesionales de la salud es cambiar la clasificación de los pacientes, centrándose en una identidad común compartida. El profesional de la salud debe hacer preguntas sobre otras identidades sociales como pasatiempos, intereses, ocupación, desviando así su atención de la etnia del paciente. Esto puede ayudar a inhibir estereotipos negativos implícitos. Además, otra estrategia para reducir la activación del sesgo implícito puede ser tomar la perspectiva del otro lado, en este caso, del grupo minoritario. Algunos casos han demostrado que cuando una persona se imagina que se encuentra en la difícil situación del otro lado, es más probable que sea empática y adopte una concepción más satisfactoria como resultado. Algunos talleres que entrenan este aspecto, involucran a los participantes haciéndoles ver una imagen de un grupo minoritario y escribir una historia donde pasan un día en la vida de ese paciente.[49] También hay evidencia de que el aumento de la diversidad de profesionales de la salud ayuda a reducir los prejuicios raciales y étnicos.[50]

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Ethical Issues Concerning Informed Consent in Translational/Clinical Research and Vaccination Bias and Informed Consent

Aspectos éticos del consentimiento informado en la investigación translacional/clínica y sobre el sesgo o prejuicio en los ensayos clínicos

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Abstract

Improving the health literacy of patients in relation to medical practices and research is essential for upholding the principle of respect for autonomy—that is, respecting the patient's ability to make self-governed choices regarding medical interventions or research participation that reflects the patient's beliefs and values. This paper considers the challenges of informed consent (i.e. ethical gaps, barriers, and priority needs) that are unique to cer-

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This paper has been elaborated under i-CONSENT project that has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 741856: www.i-consentproject.eu
Received on March 06, 2019. Accepted on March 08, 2019.

tain vulnerable groups, namely preadolescents, adolescents, and pregnant women, with a specific emphasis on how neurobioethical, multicultural and interreligious variables should be taken into account when assessing the appropriateness of the current documents relying on the notion of informed consent. In exploring how we are to improve the process of obtaining informed consent, this contribution pays particular attention to the relevance of bias and privacy in the debate, suggesting new ways of intervening so to reduce the effects of implicit bias.

Key words: Autonomy, Bias, Bioethics, Competence, Informed consent, Vaccination

Introduction

Informed consent process requires of four characteristics to be valid: voluntariness, disclosure, understanding and capacity. Whenever one of these elements is missing, informed consent can be compromised.[1]

Voluntariness, meaning that patients must make the decision to participate without influences or coercion and understanding that they are under no obligation to participate, and if they do, they have the right to withdraw at any time.[2] [3]

Disclosure means giving subjects all the relevant and right information about the research, including the risks, potential benefits, nature and other therapeutic alternatives. According to the ethical considerations of the Belmont Report, the following principles are specifically relevant in terms of the existing issues when disclosing the information in the informed consent obtaining process. The principle of autonomy and obligation truth-telling, places disclosure on always providing the complete information to every patient. However, based on the principle of beneficence and the principle of non-maleficence, usually the right approximation to do is only partial disclosure. The principle of justice is not considered here when analyzing disclosure due to its more limited relevance with this issue.[4] [5] Understanding involves that participants have the ability to comprehend the information and perceive the relevance into their personal lives under reasoned conditions. In other words, appropriate, precise and relevant information should be provided in a language and format that patients fully understand.[6] [7] [8] Capacity in any clinical situation means to be capable of making autonomous decisions and engage into a clinical trial under reasoned deliberations, comparing the risks and benefits of the procedure. A patient needs to have the capacity of self-determination to reflect, decide and consider, when deciding to participate in a clinical trial.[9] [10] Capacity can also be considered as a sliding scale, where not all the decisions need the same level of capacity. In this way, a patient could have the capacity to make a decision but not another. As the importance of the decision increases, and the information given is more specific and accurate, the threshold for considering a patient capable, is also higher. For instance, a life-or-death decision with clinical and technical information, would have a high threshold for capacity and the patient would need to show the required level of ability to reason the decision-making process.[11] [12] In the following section, the role that investigators can have (with their bias) in the obtainment of informed consent will be explored more in detail.

What is bias?

A patient should receive a different care attention relative to his or her specific ethnic group, gender or any other factor. However, there are existing bias, among health care professionals that contribute to health disparities.[13] [14] Bias refers by psychologists as «the negative evaluation of one group and its members relative to another».[15]

A stereotype is «a cognitive structure that contains the perceiver's knowledge beliefs, and expectations about a human group».[16] The reason why people have stereotypes is because it is a way to simplify the processing and storing of information in a more efficient way in terms of mental energy and time consuming. It has been found that repeated stereotyping leads to a psychological system where consciousness disappears and becomes implicit even when a person is educated in multicultural diversity and has no conscious negative attempts to use their stereotypes.[17]

There are two types of bias: explicit and implicit. The explicit bias is the one that the person has awareness of, and it is associated with deliberative behaviors (e.g. verbal). In the last 50 years, explicit bias in terms of ethnic background or religious beliefs have decreased significantly, being nowadays unacceptable within general society.[18] However, implicit bias, is the one that makes a person acts unintentionally, unconsciously and makes negative associations and judgements without awareness. This kind of implicit bias is persistent and common in the society and it is difficult to control. Implicit bias is normally associated with spontaneous non-verbal behavior such as repeatedly eye contact, sitting away from a person that is not from the same ethnic group as yours, facial expression, and so on. For instance, a person could think that he or she is not racist but then, has unintentionally attitudes that makes him or her act in a prejudiced manner. This non-conscious behavior can influence in the decision-making, health-care professionals and patient's perceptions, and thus, in the quality of care. Implicit racial attitudes have been considered as one of the reasons that may explain why clinicians provide less quality care to patients from a different ethnic background, even when they fully intend to give equal care to everybody.[19] [20] [21] [22] [23]

Recruitment of minorities

Recruitment in research is influenced by several factors that need to be identified in order to improve this process.[24] When talking about minorities, recruitment for clinical trials have even more barriers and gaps that need to be addressed.[25] Clinical investigators have found it difficult to enroll patients from minorities due to a mistrust relationship, language differences, cultural values and limited access to these populations.[26] In this way, a study that interviewed and look for experiences and perspectives of principal investigators, research staff, referring clinicians and cancer center leaders, showed that multi-level barriers are often faced by minorities that exclude them from being offered an opportunity to participate in a clinical trial. Language discordance was one of the barriers where investigators suggested that the time and effort required with translators could discourage others from even offering the trial to these patients.[27]

One qualitative study performed in London where three clinical research teams were interviewed, showed that there were four themes influential to recruitment: infrastructure, nature of the research, recruiter characteristics and participant characteristics. Focusing on the recruiter characteristics it was noticed that none of the recruiters had received specific training in recruitment. There was a discussion on whether or not this training could affect the recruiter skills or could be useful to improve them. At the end, it was said that an individual's personality was crucial to their recruitment success, meaning that it is an aspect difficult to teach. This suggests again that there is an existing investigator bias that can affect in the recruitment and in consequence in the informed consent obtaining process, as every person is different and thus, can influence in offering or not the participation in a clinical trial to a potential subject. Furthermore, no specific strategies are normally employed for the recruitment of patients from different ethnicities or socio-demographic backgrounds due to the belief that recruiters invite all eligible patients to participate, despite of their background. However, the truth is that recruiters tend to stereotype potential participants based on their previous experiences and choose not to go towards individuals who are otherwise eligible.[28]

A research group from United Kingdom (Centre for Population Health Sciences of the University of Edinburgh; the National Heart & Lung Institute and the Division of Epidemiology of the Imperial College London; and the Medical Research Council (MRC)- Asthma UK Centre for Allergic Mechanisms in Asthma of the Barts and The London School of Medicine and Dentistry) conducted a qualitative case study where a comparison between United States and United Kingdom is done in terms of multiculturalism and multi-ethnic attitudes when recruiting minorities into research. This study is considered particularly relevant in this report, since United States is a reference country with high differences in multi-ethnic and multiculturalism population and also large experience in conducting clinical trials. The study consisted on interviews with 19 researches from UK and 17 from US. Results revealed a wide gap between both countries in terms of policy, attitudes, practices and experiences in relation to the inclusion of ethnic minorities in research. The study showed evidence of UK researchers having a lot of stereotypes and prejudices that were negatively influencing on the recruitment process of ethnic minorities. For instance, one researcher presented ethnic minorities as lacking altruism stating that this population were more focused on their families rather than on society as a whole, describing south Asian people as «a little bit selfish».[29] This gap between US and UK (to an extent linkable to much of Europe) could be explained by the presence in US of the NIH policy in relation to recruitment of women and minorities in clinical trials, that places a responsibility on investigators to ensure that women and members of minorities and their subpopulations are included in all human research not allowing cost as a reason for excluding them and initiate programs and support for outreach efforts to recruit these groups. The absence of such a policy in UK, with the prejudices and stereotypes, contribute to the under-representation of these groups in the clinical trials, and thus, to the existing investigator bias in the informed consent obtaining process.[30] Besides, clinicians can also find difficulties to provide the information to their patients, because they worry about information being frightening in some cases. For this reason, the investigator's attitude can lead to a biased recruitment selecting patients that they consider «easier» to communicate with.[31]

Researcher influence

Patient decision making process could also be influenced conscious or unconsciously by the investigator. This is so, that various reviews have shown that researcher influence is one of the most provocative variables in patient participation in clinical trials. Patients tend to accept participation when they have a good relationship with the investigator and a reliable relation is built between them. Nevertheless, when patients do not trust their physician, or the physician even discourage them, they are more likely to decline participation.[32] In this way, informed consent is also influenced suggesting that patients are not being objectively informed, and their consent is being influenced by the investigator and other external factors. There is also another kind of bias, called optimism bias which has been seen in patients but also in investigators. This kind of bias is more likely of phase I clinical trials where patients normally do not have another alternative to treatment and accept to participate in research because it's the only choice. In this context, ethical issues arise in whether these patients are consenting without understanding really the trial's purpose or without enough information to make an informed consent decision. For instance, in phase I cancer subjects, optimism bias is commonly found. They hope their own chance of obtaining high medical benefit. Sometimes, even investigators are not immune to therapeutic optimism bias. Despite of their predictions about survival, they show an optimism bias when it comes to patients they know better or they have treated longer. This optimism bias is one of the most consistent in psychology and its consequences are shown in patients willing to participate and investigators willing to propose the clinical trial.[33]

Limits of disclosure

Another aspect to consider are the limits of disclosure in informed consent. For now, it has only been discussed the point of view where the investigator's opinion, views, and characteristics can influence on the decision-making process of a potential subject. However, other opinions and reviews state that unless subjects are informed of these investigator's personal characteristics, views and sponsors, their autonomy is being overridden, meaning that subjects could consider the information about researchers important to their decisions. But then, there is also the issue of the investigator's privacy not being respected and the doubt of his or her characteristics not being discriminated.[34]

There are differences in how people understand, accept and react when confronting bad news, or even cultures where giving bad news is not allowed, whereas others think that every kind of information is needed to know, etc. For these inconsistent opinions, disclosure of information should be thought carefully and considering these questions: Who? Where? What? How?[35]

Regarding who should disclose the information, the doctor that best knows the patient should.[36] Where? It should always be disclosed in a private and quiet room, not in the middle of the corridor or in front of other people.[37] What? The relevant and adequate information in each case should be disclosed, whatever is the best for the patient.[38] How? The information should always be disclosed in a sensitive and empathic way, considering also the body language, non-verbal behavior, the wording. Also, patients need to have their time to process the information and a return visit if they wish.[39]

Ethnic/racial implicit bias: neuroscientific approach

We have seen in the previous sections that both neuroscience and cultural background are important variables to take into account when assessing informed consent -and this applies also for what concerns implicit bias. In general, clinical investigators and health care professionals show respect for other cultures and ethnicities, but when applying it to real situations and clinical research, a lot of gaps are identified. This suggests that there is an unconscious bias and stereotyping that lead to the difficulties in communicating, enrollment and informed consent process when other cultures and populations are involved.[40]

It has been seen that when health care professionals have the appropriate time to process the information, enough cognitive resources and the required motivation to avoid bias and prejudices, the care attention they provide is equal within different patients and it is not influenced by implicit bias. However, these implicit attitudes can influence in the behavior and cognitions when the cognitive process capacity is altered by factors such as anxiety, stress, illness, fatigue or cognitive overload. Moreover, in this context, when cognition capacity is loaded too much, people are more likely to stereotype and follow automatic categorizing due to the memory being biased towards implicit attitudes, difficult to override. For this reason, it is important to take this into account in clinical/medical contexts, where it is easy to have situations under stress, time pressure and working memory, that can lead to a cognitive overload, and thus, to a biased behavior.[41] [42]

A plethora of different studies that were conducted in different countries found evidence of existing implicit bias among healthcare professionals, using different testing methods and studying various socio-demographic characteristics. The results showed that the higher the level of implicit bias was, the poorer was the quality of care. There is clear evidence for a relationship between implicit bias and negative effects on patient interaction, but, although this does not always have to mean a bad treatment, the truth is that, a good relationship between patient and healthcare professional is crucial to provide a good treatment.[43] Another study stated that implicit racial bias in favor of white people over blacks showed less patient-centered attitudes in clinicians, with a less emotional tone and negative communication that rated as poor the care of the visit.[44]

In fact, results have shown that the majority of implicit ethnic bias are favorable to whites over blacks and that these attitudes are different between males or females health care professionals, being stronger for males, which have stronger preferences for whites on explicit and implicit racial attitudes.[45]

Future steps

Implicit bias can be considered as an automatic association between two terms (cue and response). It has been shown that trying to change the association is more effective than trying to change the response itself, because implicit bias is difficult to control and even if physicians are convinced to consciously reduce their perceptions and implicit bias, it is not guaranteed that they have deleted it and they may re-appear again after a while. In this way, there are some findings where admired African Americans are presented to whites and afterwards, implicit bias is reduced. This technique needs to be translated into clinical contexts, but it suggests a possible way to address the bias.[46] [47]

Another possible intervention could be to address the stereotype threat that some patients have which have been shown that may altered patient-researcher communication and thus, increase mistrust. Actions that decrease patient's insights of threat are needed. Self-affirmation is the process where the self-integrity values are affirmed, and it is sometimes used in educational fields to decrease racial issues. Hence, self-affirmation could help reduce the implicit bias and improve patient-researcher relationship.[48]

Emerging research has shown that explicit cognition can be used to control and mitigate implicit attitudes. Considering this, one of the strategies suggested for health care professionals, is to change the categorization of the patients, focusing on a shared common identity. The health care professional should ask questions about other social identities such as hobbies, interests, occupation, and shifts his or her attention from the patient's ethnicity. This can help to inhibit the implicit negative stereotypes. Moreover, another strategy for reducing the activation of implicit bias can be taking the perspective of the other side, in this case, the minority group. Some findings have shown that when a person imagines to be in the difficult situation of the other side, he or she is more likely to be empathic and adopt a more approving conception as a result. Some workshops that train this, involve viewing a picture of a minority group and write down a story where they spend a day in the life of that patient.[49] There is also evidence that increasing the diversity of health care professionals help to reduce racial and ethnic biases.[50]

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Liderazgo en medicina: uniendo competencias sociales a valores morales

Leadership in medicine: linking soft skills o moral values

Antonio Marturano

Resumen

El liderazgo en medicina es todavía un campo poco explorado en Italia; mientras este tema es de creciente importancia global en el ámbito del cuidado de la salud, su impacto en el área académica italiana aún está limitado a enfermería, y solamente algunos cursos están disponibles. A nivel mundial, el liderazgo en el cuidado de la salud se iguala a poseer habilidades de competencia social; por el contrario, en Italia, los eruditos aún ligan el liderazgo con habilidades técnicas. En este documento, nos proponemos abordar el problema del liderazgo en medicina de una manera más general: la creciente complejidad de actividades administrativas en el cuidado de la salud pone nuevos retos a la profesión médica, que hoy en día requiere no solamente poseer competencias sociales, sino también habilidades en la implementación organizacional, social y de valores profesionales, que necesitan una conciencia moral basada en un liderazgo en transformación.

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Publicado por la revista *Medicina e Morale.* La traducción no fue revisada por el autor.
Recibido el 30 de enero de 2019. Aceptado el 12 de febrero de 2019.

Palabras clave: liderazgo en medicina, competencias sociales, ética de liderazgo, liderazgo transaccional y en transformación.

1. Introducción: El surgimiento del liderazgo en medicina

El estudio de liderazgo es una disciplina de creciente importancia en muchos sectores profesionales, y es de una creciente importancia académica hoy en día [1]. El estudio del liderazgo en medicina ha iniciado hace poco a tomar su lugar como un término médico común [2]. Como Dowton lo advirtió desde hace algunos años, "el liderazgo ha recibido poca atención en […] literatura médica arbitrada." [3]. Las cosas han cambiado: la literatura de liderazgo en medicina ha aumentado dramáticamente en años recientes. El interés en el liderazgo en medicina fue disparado por el cambio en el clima organizacional: desde las formas anticuadas a las nuevas formas de gobierno [4:2], que llevó a una creciente participación de los médico no solamente en administración general [5], sino que también por el desplazamiento de la Práctica General (a menudo referida como "medicina de cabecera") hacia la forma más centralizada de prestación de la atención médica tal como la medicina hospitalaria [2]. Al mismo tiempo, "surgen nuevos retos de salud. Nuevos riesgos de infecciones, medioambientales, y de comportamiento, en tiempos de rápido crecimiento y transiciones demográficas y epidemiológicas, amenazan la seguridad de salud de todos. Los sistemas de salud a nivel mundial están luchando por mantenerse, a medida que se vuelven más complejos y costosos, imponiendo demandas adicionales en los trabajadores de la salud" [6].

El liderazgo, en esos países pioneros (tales como el Reino Unido y los Estados Unidos de América) que están enfrentando cambios en el Sistema Nacional de Salud, parece que están equiparando el liderazgo a habilidades diferentes de las que son solamente habilidades médicas practicas; en otros países más tradicionales, tales como Italia, el liderazgo en medicina parece generalmente que aún se equipara con habilidades técnicas.[1] De acuerdo con Warren y Carnall, "el buen liderazgo médico es vital para proveer un cuidado de salud de alta calidad,[2] y aun así el progreso en la carrera médica ha tradicionalmente visto el liderazgo con poca credibilidad comparativamente con las habilidades técnicas y académicas" [7].

De hecho, el liderazgo en medicina no se refiere a habilidades técnicas, que son las habilidades específicas de un médico profesionalmente entrenado, sino que, de acuerdo con la idea general dominante del liderazgo, ello involucra aspectos organizacionales (tales como una relación líder-seguidores) y las así llamadas competencias sociales (tales como la persuasión, motivación, negociación, redes sociales, y así sucesivamente)[3] a través de todas las profesiones médicas [8] [9]. En efecto, sin estas habilidades sociales, la aptitud técnica y la inteligencia empresarial no valen mucho si los líderes no tienen habilidades para ejecutarlas; en otras palabras, las competencias sociales son necesarias en apoyo al profesionalismo existente, a fin de lograr un liderazgo [10].

En su discurso de James Mackenzie 2010, Sir Lewis Ritchie argumenta los rangos de importancia del liderazgo desde la práctica general a la enfermería y hasta los servicios hospitalarios. Sin embargo, "la consulta de pacientes se mantiene en el centro de la práctica clínica, pero ahora está siendo dada en diferentes formas, bajos nuevos arreglos, y por un equipo creciente de profesionales de la salud. El potencial excepcional de la práctica general continua desenvolviéndose, incluyendo cuidados anticipados y promoción de la salud, adicionalmente a nuestro rol tradicional de aliviar el sufrimiento, el dolor, y la angustia" [11]. De acuerdo con Frenk y otros autores (*et alii*), "todo profesional de la salud en todos los países deberá ser educado para movilizar el conocimiento, y para involucrarse en razonamiento crítico y en conducta ética, a fin de que sea competente para participar en sistemas de salud centrados en el paciente y la población, como miembros de equipos local-mente responsivos y globalmente conectados" [6]. En otras palabras, el liderazgo en medicina deberá incluir la idea de una medicina centrada en la persona, en la cual el elemento moral es un ingrediente fundamental, como lo sugiere Ramsey [12], y es tan importante como las competencias sociales, como lo discutiremos al final de este documento.

2. Definiciones de liderazgo y de competencias sociales

Mientras que la literatura sobre liderazgo en medicina se enfoca básicamente en las competencias sociales, la naturaleza misma (ejemplo: "el problema de definición") del liderazgo es todavía un asunto controvertido.[4] John Nye experto en liderazgo político [14: X], declara que has cerca de 211 diferentes definiciones de liderazgo (de la literatura de los Veintes a los Noventas del siglo pasado). Por otro lado, Rost, un crítico académico de los estudios de liderazgo, concluye que, viendo la prensa popular, el liderazgo es una palabra "candente", la cual "ha llegado a significar toda clase de cosas para toda clase de gente" [15:7]. Peter Drucker, uno de los pioneros de los estudios en administración, declaró su famosa expresión "La única definición de un líder es alguien que tiene seguidores. Algunas personas son pensadores. Algunas son profetas. Ambos roles son importantes y muy necesarios. Pero sin seguidores no puede haber líderes" [16]. En tanto es controversial, la definición propuesta es formalmente correcta: lo que sea que queramos decir con funciones de liderazgo en una profesión en particular (o en un ambiente de liderazgo), el liderazgo se dispara únicamente cuando alguien obtiene seguidores: sin seguidores no hay liderazgo. Podemos llamar a esta definición "una definición de liderazgo mínima" [17]; cualquier aplicación de liderazgo en un campo en particular hace surgir habilidades específicas que caracterizan a un líder en ese profesionalismo en particular. Así como Warren Bennis, uno de los pioneros en estudio de liderazgo, explicaba « Hasta cierto punto, el liderazgo es como la belleza. Es difícil de definir, pero lo reconoces cuando lo ves» [18]. John Kotter, [19] profesor de la Escuela de Negocios de la Universidad de Harvard, define el liderazgo por lo que los líderes hacen: asumen el cambio, establecen la dirección, alinean gente que participe en esa nueva dirección, y motivan a la gente. La misma dificultad se encuentra cuando alguien intenta definir el liderazgo clínico en medicina. De acuerdo con LAl y otros, el concepto de liderazgo clínico puede ser definido en una variedad de formas; y mientras la definición estándar de liderazgo clínico, que está absolutamente de acuerdo en su significado, no es crucial para el progreso y es probable que sea difícil, es útil considerar las diferentes formas en que el liderazgo clínico es conceptualizado y presentado en la literatura. Mientras que el liderazgo clínico efectivo ha sido ofrecido como una manera de asegurar un cuidado óptimo y superar los problemas del área de trabajo clínico, una definición estándar de lo que define un liderazgo clínico efectivo se mantiene esquivo" [20].

Los "problemas de definición" concuerdan también con cómo se desmarca el liderazgo de la administración. Esto es un delicado debate en los estudios de liderazgo discutidos desde su infancia, y aun así no has un punto de vista concordante en lo que los administradores o líderes deben de hacer y que necesitan hacer. De acuerdo con G. Salaman, "nunca podrá haber, puesto que tales definiciones no surgen de requerimientos organizacionales o técnicos (que ellos mismos son producto de la teoría administrativa de la organización), sino que surge de las formas cambiantes en que a lo largo del tiempo estas funciones han sido conceptualizadas de maneras diferentes" [21]. Por el contrario, en su documento fundamental, A. Saleznik distingue claramente líderes de administradores, de acuerdo con sus tareas y sus roles en las organizaciones: Estos últimos tratan con las tareas rutinarias del día a día, que están ligadas a su rango organizacional, "asegurándose de que el negocio diario de la organización sea realizado" [22]. Por otro lado los líderes, "adoptan actitudes activas personales, hacia los objetivos. Ellos buscan oportunidades potenciales y recompensas que yacen a la vuelta de la esquina, inspirando a sus subordinados, y disparando el proceso creativo con su propia energía" [22]. John P. Kotter también agrega otros dos elementos que nos ayudan a distinguir entre líderes y administradores: "La administración trata acerca de ajustarse con la complejidad" [19]; su alcance es traer un grado de orden y consistencia a las dimensiones organizacionales clave. "El liderazgo, en contraste, trata acerca de ajustarse al cambio" [19], tal como el cambio en la estructura propia de las organizaciones, que necesita encajar con nuevas condiciones sociales y económicas y con el cambio tecnológico. Estas diferentes funciones, de acuerdo con Kotter, perfilan las actividades características de la administración y el liderazgo. Lewis Richie define el liderazgo más ampliamente como «la habilidad para influenciar y motivar a la gente» y describe a los líderes como gente que "afronta el cambio, ellos establecen una visión y una dirección, y estimulan a los miembros del equipo a seguir esa visión" [11]. De acuerdo con Rughani y otros, "Richie hace una conexión entre el profesionalismo (médico) y el liderazgo, y debemos pensar en esto como algo que está entrelazado con el liderazgo, siendo ambos parte del comportamiento profesional central, y un impulsor de su reforma continua" [23].

En resumen, la administración parece ligada a competencias rutinarias relacionadas con el rol de una persona dentro de una organización, con el objetivo de mantener aceitada la maquinaria organizacional, mientras que el liderazgo está más relacionado con la visión, el cambio[5] y el factor humano en una organización. Sin embargo, la naturaleza cambiante de los retos encarados por las sociedades del siglo XXI impulsan nuevos enfoques a la gobernanza y al liderazgo; Kickbusch y Gleicher sostienen que «la salud es únicamente un reto, y no siempre se le da prioridad. Sin embargo, la mayoría de estos retos tienen efectos significativos en la salud, que no han sido suficientemente tomados en cuenta hasta ahora. Los retos incluyen *shocks* sistémicos, tales como desastres naturales y el brote de enfermedades, así como procesos de largo plazo, tales como la urbanización, transiciones demográficas y epidemiológicas, inseguridad en la alimentación, cambio climático y las crecientes disparidades económicas» [4: VII-VIII].

Lo que es muy importante es que recientemente la literatura sobre el liderazgo se ha enfocado en las competencias sociales o poderes (opuesto al fuerte poder que está ligado a la autoridad, a la posición jerárquica en las organizaciones y la coerción); estos poderes o habilidades surgen de dos hechos diferentes, aunque convergentes: el desplazamiento del paradigma militar-industrial en macroeconomía, y la importancia creciente y compleja de la información, y de la forma en la cual eso debe ser comprendido, elaborado y entregado [14: 45]. De acuerdo con Kickbusch y Gleicher, el vivir en una sociedad compleja basada en la información "quiere decir que el poder y la autoridad no están ya más concentrados en el gobierno. Los ciudadanos informados, los negocios y empresas conscientes, las agencias independientes y las organizaciones de expertos cada vez aumentan su rol participativo. Sin embargo, los gobiernos y los ministerios de salud continúan siendo importantes en la administración de la gobernanza de la salud, en el establecimiento de normas, en el proporcionar evidencias, y en hacer de la opción más sana, la opción más fácil" [4: VIII]. El centralismo del trabajo de un líder se desplazó de las habilidades relacionadas con la autoridad formal, hacia competencias sociales que permiten a un líder usar información, para persuadir y atraer seguidores.

En el liderazgo gerencial y político, las competencias sociales no son tan centrales, como en el campo de la medicina. Mientras que cierta cantidad de habilidades fuertes o duras (habilidades que están conectadas a la posición formal dentro de una jerarquía) se requiere en la profesión médica, son menos importantes que la administración. La interacción con colegas y con pacientes pide, como en las universidades, una jerarquía más plana, porque la complejidad, la posesión de conocimiento[6] y el compartirlo con sus colegas requiere un enfoque diferente y más democrático que en la administración [14: 31], o aun requiere de un liderazgo disperso [4: VII].

Ciertamente, de acuerdo con Nye, el liderazgo político y administrativo se beneficia de la interrelación entre los poderes fuertes y suaves, que Nye llama *(smart power) poder inteligente* (14: X), que es una combinación de habilidades derivadas de la posición personal (esencialmente coerción y recompensas) y esas habilidades personales que hemos visto más arriba.

Por lo tanto, hay un acuerdo general de que las habilidades suaves son muy importantes para el liderazgo en medicina, especialmente en una organización tal como lo es un hospital, en el cual los médicos tienen que batallar diariamente con emergencias clínicas, cuidado de pacientes y relaciones sociales con sus colegas. Ciertamente, Rughani y otros sostienen que "La práctica general está caracterizada por la incertidumbre y la complejidad, y opera a través de relaciones con un amplio rango de gente, con quienes la colaboración es un principio clave" [23].

¿Qué son estas competencias sociales? De acuerdo con Warren y Carnall, los médicos deberían «tener la posibilidad de tomar una vista macroscópica de la provisión de cuidados de la salud y de asignación de recursos, y de entender los impulsores políticos, económicos, sociales y tecnológicos del cambio que influenciará esta visión a lo largo de sus carreras. Los médicos, a quienes hasta ahora se les ha enseñado poco del Sistema Nacional de Salud (NHS), tendrán la necesidad de aprender acerca del fondeo, organización, gobernanza y administración, que son parte integral de sus labores. Necesitan ser apoyados por sistemas bien desarrollados, lineamientos claros para reportar información y responsabilidad, y una cultura organizacional que proporcione buena información y motive su uso, como un vehículo para mejorar el desempeño. Finalmente, todos los médicos, ya sea que continúen predominantemente como practicantes médicos, se movilicen para dirigir organizaciones o asumir roles más estratégicos, pues necesitan aprender más acerca de "seguimiento al líder" (*followership*) […], que reconoce la importancia de la participación y de permitir a otros para que dirijan [7]. Más aún, Warren y Carnall sugieren, sin embargo, que estas habilidades necesitan ser apoyadas por “una amplia gama de habilidades no técnicas para permitir a (futuros líderes médicos) otros que dirijan, no solo dentro de la medicina, sino a través de todos los límites profesionales” [7]. Básicamente, las competencias sociales requieren que los médicos “creen y comuniquen su visión, estableciendo una clara dirección, el rediseño del servicio y el mejoramiento del cuidado de la salud, la negociación efectiva, el estar consciente tanto de otros como de ellos mismos, el trabajar colaborativamente y en redes. Necesitarán tener la habilidad de equilibrar muchos intereses y prioridades diferentes en competencia, y administrarse ellos mismos efectivamente; para ampliar la credibilidad de sus colegas, muchos tratarán de continuar proporcionando cuidados clínicos de alta calidad a la par de estas posiciones prominentes de liderazgo. Ellos deben mantener, la voz y la práctica de fuertes valores morales personales, y creencias que impacten positivamente en aquellos alrededor de ellos, y colocar al paciente en el centro de la toma de decisiones, y no las prioridades del proveedor” [7].

Mientras surge un consenso general acerca de los objetivos de las competencias sociales en el liderazgo médico, no hay un consenso sobre qué competencias en particular debiera poseer un líder médico: algunos eruditos enfatizan sobre la habilidad de crear una visión [1; 9]; algunos en crear confianza [11]; otros sobre empoderamiento [8], y otros, especialmente aquellos que trabajan con enfermería, en las emociones [20] o sobre la inteligencia emocional [24]; la importancia de un rango en particular de competencias sociales, no únicamente sobre las relativas a la profesión médica, sino también, como sucede en el liderazgo, más generalmente, en el contexto cultural y organizacional.

3. Liderazgo en medicina y valores morales: la teoría normativa

Hemos declarado que, paralelamente al desarrollo de las competencias sociales, aquellos involucrados en el liderazgo en medicina, deberían desarrollar una mayor sensibilidad por los valores. Los valores "pueden ser definidos como amplias preferencias por cursos apropiados de acción o resultados; por lo tanto, ellos reflejan el sentido de una persona sobre el bien y el mal, y en lo que debe ser. Los valores influyen en las actitudes y en el comportamiento, y debido a eso conforman la formulación de políticas y sociedades enteras, mediante el establecimiento de reglas y normas (los principios) que determinan lo que son acciones aceptables (esto es, éticas), en las áreas familiar y comunitaria, o en términos de la gobernanza de la sociedad, y en las interacciones entre comunidades y sociedades con diferentes valores y principios" [4: 47-48]. Ciertamente, Ritchie argumenta que "correctamente los pacientes han incrementado las expectativas de involucramiento, rendición de cuentas y transparencia, pero también tienen responsabilidades así como derechos" [11]. No es del todo raro que Ritchie regrese a la *República de Platón*, cuando describe al líder ideal. Ritchie sostiene: "el filósofo griego Platón, quien primero definió al líder ideal como alguien que se compromete a, y es entrenado para, un vida de servicio y devoción para sus conciudadanos" [11]. El líder ideal de Platón "tiene resonancia inmediata sobre nosotros como médicos generales, el enlace entre compromiso, educación continua (o auto-renovación), y las necesidades de nuestros pacientes. Independientemente de los cambios científicos, políticos o de la sociedad, nuestras credenciales de liderazgo deben estar fundamentadas en el baluarte duradero de nuestros valores morales y en las obligaciones hacia pacientes y sociedad. Estos valores y obligaciones se suman a nuestro "profesionalismo" como Médicos Generales" [11].

Esta llamada a los valores morales en el liderazgo en medicina no implica únicamente temas ya discutidos en bioética y en ética médica, como ya sucede en enfermería [24], sino que también incluye discusiones recientes acerca del rol de la ética en el liderazgo (Ética del Liderazgo). La ética del liderazgo, ciertamente sostiene que la ética es importante para el estudio del liderazgo que inició las así llamadas teorías de liderazgo. Las teorías normativas del liderazgo fueron propuestas y son famosas por –entre otros– el politólogo James MacGregor Burns [25], y tomado como punto de partida de la dimensión ética/moral del liderazgo; los eruditos involucrados en esta escuela deben creer que la ética es un elemento crucial de liderazgo o inclusive, el elemento esencial del liderazgo [26: 15], porque ningún liderazgo puede ser efectivo sin ser al mismo tiempo ético; y porque la opción –y por lo tanto el daño moral– es coincidente con el liderazgo.

De acuerdo con James MacGregor Burns, se pueden distinguir dos clases básicas de liderazgo: *liderazgo transformante y transaccional.*

Burns caracteriza el *liderazgo transaccional,* en términos de la noción de intercambio: "Dicho liderazgo ocurre cuando una persona toma la iniciativa de hacer contacto con otros, con el propósito de un intercambio de cosas valiosas. El intercambio podría ser económico o político, o psicológico en su naturaleza: una permuta de bienes, o un bien por dinero; una transacción de votos entre candidato y ciudadano o entre legisladores; la hospitalidad hacia otra persona, a cambio de la voluntad de escuchar nuestros problemas. Cada parte de la negociación, está consciente de los recursos de poder y actitudes del otro. Cada persona reconoce al otro como una persona. Sus objetivos están relacionados, al menos en la medida en que los objetivos se encuentren dentro del proceso de negociación, y se pueda avanzar mediante el mantenimiento de ese proceso". [25: 19-20]

Burns argumenta que, la relación durará únicamente en tanto la negociación se mantenga, pero realmente no une a líderes y seguidores juntos en una lucha mutua y continua hacia un objetivo más alto. Una vez que el objetivo de la negociación ha sido satisfecho, la relación del liderazgo terminará; eso resultará en una ética de la opción e individualismo que caracteriza el mercado y (discutible) la política contemporánea [27].

Por el contrario, *el liderazgo transformante* toma otro camino: es normativo. Es normativo en dos sentidos. Primeramente, describe como los valores morales y las alternativas basadas en valores pueden ser influenciadas por las acciones de líderes, y en las formas en que los seguidores las perciben. En segundo lugar, no intenta simplemente describir cómo los líderes se comportan de hecho, sino más bien, prescribe cómo deberían ellos comportarse.[7] Burns define el liderazgo transformante como sigue: "El líder transformante reconoce y explota una necesidad existente, o una demanda de un seguidor potencial. Pero, más allá de ello, el líder transformante busca motivos potenciales en los seguidores. El resultado del liderazgo transformante es una relación de estimulación mutua, y de una elevación que convierte a los seguidores en líderes, y puede convertir líderes en agentes morales" [25: 4]. En consecuencia, de acuerdo con Burns, los líderes transformantes se dirigen hacia el movimiento más allá de los deseos de la gente y de sus voluntades, enganchando así sus necesidades reales y sus valores morales. Burns sostiene que el liderazgo transformante es la capacidad de trascender los reclamos de una multiplicidad de deseos diarios, de necesidades y expectativas, mediante la elevación tanto de líderes como de seguidores a "niveles más altos de motivación y moralidad" [25: 20]. Por eso, tanto líderes como seguidores inician principalmente del reconocimiento de valores morales compartidos, que ellos utilizan para acciones colectivas. El erudito pionero del liderazgo ético, J. Ciulla, sostiene que "la teoría de Burns del liderazgo transformante […], descansa en un conjunto de supuestos morales, acerca de la relación entre líderes y seguidores. La teoría de Burns es claramente una prescripción acerca de la naturaleza de los buenos líderes morales" [26]. Lo muy importante, de acuerdo a Ciulla, es que los líderes transformantes de Burns "tienen valores muy fuertes.[8] Ellos no diluyen sus valores y sus ideales morales por consenso, sino que ellos elevan a la gente mediante el uso de conflictos para enganchar seguidores, y ayudarlos a revalorar sus propios valores y necesidades" [26]. En otras palabras, los líderes transformantes de Burns están transformando, debido a que encuentran una resonancia entre sus propias creencias morales y las de otros, de tal manera que aquellos otros se vean a sí mismos como seguidores. La fuerza motivacional para el líder y los seguidores empieza con valores morales compartidos, moralidad y creencias que crean confianza no únicamente entre los médicos practicantes y los pacientes, sino también entre colegas.

4. Conclusiones

El comportamiento ético en el liderazgo a través de las profesiones médicas es fundamental; por ejemplo, en enfermería, un estudio empírico Italiano demostró que "el liderazgo ético actúa en el comportamiento organizacional de las enfermeras [...]. El comportamiento organizacional de las enfermeras es crucial en el resultado del servicio en el cuidado de la salud. Por lo tanto, el liderazgo ético afecta indirectamente la calidad del cuidado y la curación ofrecida a los pacientes" [24]. Más importante aún, la literatura general acerca de liderazgo en medicina parece converger en la importancia de las competencias sociales, pero seguramente ellas necesitan caminar mano con mano con los elementos morales basados en el liderazgo transformante. Aunque algunas competencias sociales (tales como la creación de confianza, la negociación y la concientización), requieren algo de sensibilidad ética. Aunque en administración el punto de vista de los accionistas pone por delante la utilidad, para la especial sensibilidad moral del liderazgo en medicina (que también es parte de la tradición médica desde el juramento hipocrático) juega un papel fundamental: "La medicina no es un negocio, y las diferencias entre ella y una empresa comercial son profundas, aunque quizás menos bien definidas dentro del actual clima empresarial, cuando es comparado con los viejos tiempos" [1]. Como Ritchie ciertamente ha puntualizado, "el profesionalismo médico ha sido descrito como: "un conjunto de valores, comportamientos, y relaciones que sostienen la confianza que el público tiene en los médicos". Para los médicos generales, debemos incluir nuestros propios y esenciales valores profesionales […], que forman la base de un convenio moral entre los médicos generales, pacientes y sociedad y, a su vez, proporcionar el fundamento de un liderazgo efectivo en la práctica general. Mientras el mantenimiento de los valores profesionales fue visto alguna vez como la responsabilidad individual de los médicos únicamente, yo argumentaría que el éxito profesional también depende vitalmente de la cultura moral de las organizaciones en que nosotros trabajamos” [11].

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[1] Liderazgo Médico (*Leadership Medica*), una importante revista entre los doctores y practicante médicos Italianos, aún dedica la mayoría de sus páginas a las habilidades técnicas médicas, cfr. https://www.leadershipmedica.it/index.php/it/medicina/elenco-completo-degli-articoli. Recuperada 10.1.2017.

[2] La página web de la Academia de Liderazgo del Sistema Nacional de Salud sostiene: “¿Por qué se necesita cambiar el liderazgo en el Sistema Nacional de Salud? Pues simplemente porque no hay mucha evidencia en conectar mayor liderazgo con mejor atención de pacientes. Francis, Berwick, Keogh lo señalan, así como el líder académico Michael West. Todos ellos establecen un enlace entre un buen liderazgo y hacer una positiva diferencia en el cuidado del paciente, el resultado de la atención y la experiencia de la atención”; ver https://www.leadershipacademy.nhs.uk/ recuperada 10.1.2017.

[3] Esto es lo que hoy en día está siendo hecho en la Maestría de Liderazgo en Medicina Altems, ofrecida por la Universidad Católica del Sagrado Corazón desde 2016.

[4] Levine y Boaks, por ejemplo, sostienen que el asunto de la definición del liderazgo radica sólo en lo que el liderazgo es; ambos se centran en la cuestión de su relación con la ética, y es problemática. No puede ser resuelta por el curso de la acción tomada por la mayoría de los autores, ya sea disminuyendo la pregunta o contestándola preferentemente. Pero tampoco puede ser ignorada. Debe ser contestada, a fin de decirnos qué necesitamos para saber acerca de la relación entre la ética y el liderazgo, y también aterrizar esa respuesta [13].

[5] Es interesante ver cómo el cambio es defensor del sector del cuidado de la salud; de acuerdo con Frenk y otros, “durante el siglo pasado, los profesionales de la salud hicieron grandes contribuciones a la salud y al desarrollo socioeconómico, pero no podemos llevar a cabo reformas a la salud en el Siglo XXI con competencias obsoletas o inadecuadas”. El extraordinario avance en el cambio global

está alargando el conocimiento, las habilidades y los valores de los profesionales de la salud.

[6] A pesar de la tendencia de actuar en el aislamiento de varias de las profesiones, y aun en competencia entre unos y otros, por ejemplo, en el llamado "tribalismo de los profesionales": J. Frenk y otros, *Profesionales de la Salud para un nuevo siglo: transformando la educación para reforzar los Sistemas de Salud en un mundo interdependiente* [6].

[7] Antes de Burns, los eruditos académicos eran en efecto ambiguos (o no notaban este punto) con respecto a que si ellos estaban proponiendo una teoría descriptiva o normativa de liderazgo; esta ambigüedad llevó a una cantidad de contradicciones internas, de la misma manera en que las ambigüedades entre cuestiones de ética y la normativa de razonamiento en la ley conducen a falacias éticas y legales: J.B. Ciulla, *Ética de Liderazgo: Mapeo del Territorio y Id. Conversaciones y correspondencia con Burns en la ética de transformar el liderazgo* [26; 28].

[8] Burns hace una distinción entre dos principales clases de valores: Modales y valor final. Valores modales incluyen responsabilidad, equidad, honestidad y mantener una promesa. Éstas se sustentan en los valores encontrados mediante un acto. Valores finales, por lo contrario, incluyen libertad, justicia y igualdad. Estos permiten a los líderes convertir a sus seguidores en líderes: J.B. Ciulla, *Éticas del Liderazgo*… [26].

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Leadership in medicine: linking soft skills o moral values

Liderazgo en medicina: uniendo competencias sociales a valores morales

Antonio Marturano

Abstract

Leadership in medicine is still an underexplored field in Italy; while this topic is of increasing global importance in healthcare, its impact in italian academia is still limited to nursing and only few courses are available. Worldwide, leadership in healthcare is equate to possessing soft skills abilities; on the contrary, in Italy healthcare scholars still link leadership to technical abilities. In this paper, we will propose to address the problem of leadership in medicine more generally: the increasing complexity of management activities in healthcare poses new challenges to the medical profession, which actually requires not only possession of soft skills but also abilities in the implementation of organizational, societal and professional values which need a moral awareness based on transforming leadership.

Keywords: leadership in medicine, soft skills, leadership ethics, transforming and transactional leadership.

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Published in the Italian Journal *Medicina e Morale.* Translation was not reviewed by the author.
Received on January 30, 2018. Accepted on February 12, 2019.

1. Introduction: the emergence of leadership in medicine

Leadership studies is a discipline of increasing importance in many professional sectors and it is increasing academic importance today [1]. The study of leadership in medicine has only recently started to take its place as a common medical term [2]. As Dowton noticed, since a few years ago, «leadership has received little attention in […] peer-reviewed medical literature.» [3]. Things are changed: leadership literature in medicine has dramatically increased in recent years. Leadership interest in medicine was triggered by the change in the organizational climate –from old fashioned to new forms of governance [4:2]– which lead to an increasing role of doctors not only in general management [5], but also by the shift from the General Practice (often referred to "bedside medicine") towards a more centralized form of medical care provision such as the hospital medicine [2]. At the same time, «fresh health challenges loom. New infectious, environmental, and behavioral risks, at a time of rapid demographic and epidemiological transitions, threaten health security of all. Health systems worldwide are struggling to keep up, as they become more complex and costly, placing additional demands on health workers» [6].

Leadership, in those pioneering countries (such as UK and USA) which are facing change in the National Health System, seem to equate leadership to skills different than just practical medical abilities; in other, more traditional countries, such as Italy, leadership in medicine generally seems still to be equated to technical skills.[1] According to Warren and Carnall, «Good medical leadership is vital in delivering high-quality healthcare,[2] and yet medical career progression has traditionally seen leadership lack credence in comparison with technical and academic ability» [7].

In fact leadership in medicine is not about technical skills which are the specific abilities of any professionally trained doctor, but, according to the mainstream general idea of leadership, it involves organizational aspects (such us followers-leader relation) and the so-called soft skills (such as persuasion, motivation, negotiation, networking, and so on)[3] across all the medical professions [8] [9]. Indeed, without these soft skills, technical aptitude and business savvy aren't worth much if leaders don't have the skills to execute them; in other words, soft skills are needed in support of existing professionalism in order to achieve leadership [10].

In his James MacKenzie Lecture 2010 Sir Lewis Ritchie argues leadership importance ranges from general practice to nursing up to hospital services. However, «The patient consultation remains at the hub of clinical practice, but is now being delivered in different ways, in new settings, and by a growing team of health professionals. The exceptional potential of general practice continues to unfold, including anticipatory care and health promotion, in addition to our traditional role of alleviating suffering, pain, and distress» [11]. According to Frenk et alii, «all health professionals in all countries should be educated to mobilize knowledge and to engage in critical reasoning and ethical conduct so that they are competent to participate in patient and population-centered health systems as members of locally responsive and globally connected teams» [6]. In other words, leadership in medicine should include the idea of person-centered medicine in which the moral element is a fundamental ingredient, as suggested by Ramsey [12], and is as much important as soft skills, as we will argue at the end of this paper.

2. Definitions of leadership and soft skills

While literature on leadership in medicine focuses basically on soft skills, the very nature (i.e. the "definition problem") of leadership is still a controversial matter.[4] Political leadership expert John Nye [14: X] claims there are about 211 different leadership definitions (from the literature of the Twenties to the Nineties of the past century). On the other had, Rost, an academic critical of leadership studies, concludes that, looking at the popular press, leadership is a "hot word" which «has come to mean all things to all people» [15: 7]. Peter Drucker, one of the pioneers of management studies, famously stated that «The only definition of a leader is someone who has followers. Some people are thinkers. Some are prophets. Both roles are important and badly needed. But without followers, there can be no leaders» [16]. While controversial, the proposed definition is formally correct: whatever we mean with leadership functions in a particular profession (or leadership environment), a leadership is triggered only when someone gets followers: without followers there is no leadership. We can call this definition "a minimal leadership definition" [17]; any application of leadership to a particular field emerges specific skills that characterizes a leader in that particular professionalism. As Warren Bennis one of the pioneers of leadership studies, explained «To an extent, leadership is like beauty. It is hard to define, but you know when you see it» [18]. Harvard Business School professor John Kotter [19] defines leadership by what leaders do: they cope with change, they set direction, they align people to participate in that new direction, and they motivate people. The same difficulty is found when someone tries to define clinical or leadership in medicine; according to Daly and alii, «Like "leadership", the concept of clinical leadership can be defined in a range of ways; and while a standard definition of clinical leadership providing absolute agreement on meaning is not crucial to progress and is likely to prove difficult, it is useful to consider the various ways clinical leadership is conceptualized and presented in the literature. While effective clinical leadership has been offered up as a way of ensuring optimal care and overcoming the problems of the clinical workplace, a standard definition of what defines effective clinical leadership remains elusive» [20].

The "definition problems" match also with how to demarcating leadership from management. This is a vexata quaestio in leadership studies discussed since its infancy, yet there is no an agreed view on what managers or leaders should do and what they need to do.

According to G. Salaman, «there never can be, since such definitions arise not from organizational or technical requirements (which are themselves the product of manager's theory of organization), but from the shifting ways in which over time these functions are variously conceptualized» [21]. On the contrary, in his seminal paper, A. Zaleznik clearly distinguishes leaders from managers according to their tasks and their roles in organizations: the latter deals with day by day routinary tasks linked to their organizational rank, «ensuring that an organization's day to day business gets done» [22]. On the other hands leaders, «adopt personal, active attitudes towards goals. They look for the potential opportunities and rewards that lie around the corner, inspiring subordinates and firing up the creative process with their own energy» [22]. John P. Kotter, also adds other two elements that help us to distinguishing between leaders and managers: «Management is about copying with complexity» [19] its scope is to brings a degree of order and consistency to organizational key dimensions. «Leadership, by contrast, is about coping with change» [19], such as change in the very structure of organizations which needs to fit with new social and economical conditions and with technological change. These different functions, according to Kotter, shape the characteristic activities of management and leadership. Lewis Ritchie defines leadership more broadly as «the ability to influence and motivate people» and describes leaders as people who «cope with change, they set vision and direction, and stimulate team members to follow that vision» [11]. According to Rughani et alii «Ritchie makes a connection between (medical) professionalism and leadership and we should think of these as being intertwined, with leadership being both part of core professional behavior and a driver for its continual reform» [23].

To sum up, management seems linked to routinary competences linked to a person's role within an organization aiming at keeping oiled the organizational machinery, while leadership is more about vision, change[5] and the human factor in an organization. However, the changing nature of the challenges faced by 21st-century societies drives new approaches to governance and leadership; Kickbusch and Gleicher claim «health is only one challenge and is not always given priority. Most of these challenges, however, have significant health effects, which have not been considered sufficiently so far. The challenges include systemic shocks, such as natural disasters and disease outbreaks, as well as longer-term processes, such as urbanization, epidemiological and demographic transitions, food insecurity, climate change and widening economic disparities» [4: VII-VIII].

Very importantly, recent leadership literature has focused on soft skills or powers (opposed to hard power which is linked to authority, hierarchical position in organizations and coercion); these powers or skills stem out from two different, albeit convergent facts: the shift from the military-industrial paradigm in macroeconomics and the increasing importance and complexity of information and the way in which that should be understood, elaborated and delivered [14: 45]. According to Kickbusch and Gleicher, living in a complex, information-based society «means that power and authority are no longer concentrated in government. Informed citizens, conscientious businesses, independent agencies and expert bodies increasingly have a role to play. Nevertheless, governments and health ministry's continue to be important in managing governance for health, setting norms, providing evidence and making the healthier choice the easier choice» [4: VIII]. The centrality of a leader's job shifted from skills linked to formal authority to soft skills that enable a leader to use information to persuade and attract followers.

In managerial and in political leadership, soft skills are not as central as in the medical field. While a certain amount of hard skills (skills that are connected to a formal position in a hierarchy) is required in the medical profession, they are less important than management. Interaction with colleagues and patients ask, as in universities, for a more flat hierarchy because complexity, knowledge possession[6] and its sharing with peers require a different, more democratic approach than in management [14: 31] or even it requires a disperse leadership [4: VII]. According to Nye, indeed, political and management leadership benefits from the interplay between hard and soft powers which Nye calls *smart power* (14: X) which is a combination of skills derived by personal position (essentially coercion and rewards) and those personal skills we have seen above.

Therefore, there is a general agreement that soft skills are very important for leadership in medicine, especially in an organization such as the hospital in which doctors have to deal daily with clinical emergence, patient care and social relations with peers. Rughani et alii, indeed, claim that «General practice is characterized by uncertainty and complexity and operates through relationships with a wide range of people with whom partnership is a key principle» [23].

What are these soft skills? According to Warren and Carnall, doctors should «be able to take a macroscopic view on healthcare provision and resource allocation and to understand the political, economic, social and technological drivers for change that will influence this view throughout their careers. Doctors, who until now have been taught little of the NHS, will need to learn about the funding, organization, governance and management that are integral to its workings. They need to be supported by well-developed systems, clear lines of reporting and responsibility, and an organizational culture that provides good information and encourages its use as a vehicle for performance improvement. Finally, all doctors, whether they remain predominantly as medical practitioners, move to lead organizations or take on more strategic roles, need to learn more about "followership" […] that recognizes the importance of participation and allowing others to lead» [7]. Still Warren and Carnall suggest these skills however need to be supported by «a broader range of non-technical skills to allow (future medical leaders) to lead others, not just within medicine but across all professional boundaries» [7]. Basically, soft skills require doctors to «create and communic(ate) their vision, setting clear direction, service redesign and healthcare improvement, effective negotiation, awareness of both self and others, working collaboratively and networking. They will need to be able to balance many different competing interests and priorities and manage themselves effectively; to enhance peer credibility; many will seek to continue to deliver high-quality clinical care alongside these prominent leadership positions. They must hold, voice and enact strong personal moral values and beliefs that impact positively on those around them and place the patient at the centre of decision-making, not the priorities of the provider» [7].

While a general consensus emerges about the ends of soft skills in leadership medicine, there is no consensus on which particular skills a medical leader should possess: some scholars emphasize on the ability at creating a vision [1; 9], some on enabling trust [11], others on empowering [8], and others –especially those dealing with nursing– on emotions [20] or emotional intelligence [24]; the importance of particular soft skills range not only on the kind of medical profession, but also, as happens in leadership, more generally, on the organizational and cultural context.

3. Leadership in medicine and moral values: the normative theory

We have claimed that, alongside with development of soft skills, those involved in leadership in medicine should develop a further sensibility for values. Values «can be defined as broad preferences for appropriate courses of action or outcomes; they therefore reflect a person's sense of right and wrong and what ought to be. Values influence attitudes and behavior and thereby shape policymaking and entire societies by setting the rules and standards (the principles) that determine acceptable (that is, ethical) actions in the area of family and community or in terms of governance of society and interactions between communities and societies with different values and principles» [4: 47-48]. Ritchie argues, indeed, that «Patients rightly have increased expectations of involvement, accountability, and transparency but also have responsibilities as well as rights» [11]. It is not odd at all that Ritchie goes back to Plato's Republic when describing the ideal leader. Ritchie claims: «the Greek philosopher Plato, who first defined the ideal leader as someone who commits to, and is trained for, a life of service and devotion to their fellow citizens» [11]; Plato's ideal leader «has immediate resonance for us as GPs the link between commitment, continuous learning (or self renewal), and the needs of our patients. Irrespective of scientific, societal, or political change, our leadership credentials should be founded on the enduring rock of our moral values and obligations to patients and society. These values and obligations amount to our "professionalism" as GPs» [11].

This call for moral values in leadership in medicine not only implies themes already discussed in bioethics and medical ethics as it happens already in nursing, [24], but also includes the recent discussions on the role of ethics in leadership (Leadership Ethics). Leadership ethics indeed claims that ethics is central to the study of leadership which started the so called normative theories of Leadership. Normative theories of leadership were famously proposed by –among others– political scientist James MacGregor Burns [25], and taken as a starting point the ethical/moral dimension of leadership; scholars engaged in this school of ought believe that ethics is a crucial element of leadership or even, the essential element of leadership [26: 15], for no leadership can be effective without being ethical at the same time; and because choice –and therefore moral hazard– is coincident with leadership.

According to James MacGregor Burns, two basic kinds of leadership can be distinguished: *transforming* and *transactional* leadership.

Burns characterizes *transactional leadership* in terms of the notion of exchange: «Such leadership occurs when one person takes the initiative in making contact with others for the purpose of an exchange of valued things. The exchange could be economic or political or psychological in nature: a swap of goods or one good for money; a trading of votes between candidate and citizen or between legislators; hospitality to another person in exchange of willingness to listen to one's troubles. Each party to the bargain is conscious of the power resources and attitudes of the other. Each person recognizes the other as a person. Their purposes are related, at least to the extent that the purposes stand within the bargaining process and can be advanced by maintaining that process». [25: 19-20]

The relationship, Burns argues, will last only as long as the bargain will be kept but does not really bind leaders and followers together in a mutual and continuing pursuit of a higher purpose. Once the aim of the bargain is fulfilled the leadership relation will end; that will result in an ethics of choice and individualism that characterizes the market and (arguably) contemporary politics [27].

On the contrary, *transforming leadership* takes on another path: it is normative. It is normative in two senses. Firstly, it describes how moral values and value-based choices may be influenced by the actions of leaders and ways in which followers perceive them. Secondly, it does not intend to simply describe how leaders in fact behave but, rather, prescribes how they ought to behave.[7] Burns defines transforming leadership as follows: «The transforming leader recognizes and exploits an existing need or demand of a potential follower. But, beyond that, the transforming leader looks for potential motives in followers. The result of transforming leadership is a relationship of mutual stimulation and elevation that converts followers into leaders and may convert leaders into moral agents». [25: 4]. Thence, according to Burns transforming leaders aim at moving beyond people's wants and wishes, thereby engaging their real needs and moral values. Burns argues that transforming leadership is the capacity to transcend the claims of multiplicity of everyday wants, needs and expectations by raising both leaders and followers to «higher levels of motivation and morality» [25: 20]. Therefore leaders and followers mainly start from a recognition of shared moral values that they leverage for collective actions. Pioneer leadership ethics scholar, J. Ciulla argues that «Burns's theory of transforming leadership […] rests on a set of moral assumptions about the relationship between leaders and followers. Burns's theory is clearly a prescriptive one about the nature of morally good leaders» [26]. Very importantly, according to Ciulla, Burns's «transforming leaders have very strong values.[8] They do not water down their values and moral ideals by consensus but rather they elevate people by using conflicts to engage followers and help them reassess their own values and needs» [26]. In other words, Burns's transforming leaders are transforming because they find a resonance between their own and others' moral beliefs, such that those others experience themselves as followers. The motive force for leader and followers starts from shared moral values, morality and beliefs that create trust not only between GP and patients but also among peers.

4. Conclusions

The ethical component in leadership across the medical professions is fundamental; in nursing, for example an Italian empirical study demonstrated that «Ethical leadership acts on nurses' organizational behavior [...] The nurses' organizational behavior is crucial to the outcome of the health care service. Therefore, the ethical leadership indirectly affects the quality of the care and the cure offered to the patients» [24]. More importantly, the general literature on leadership in medicine seems to converge on the centrality of soft skills, but they very likely need to walk hand in hand with the moral elements based on transforming leadership. Even though, some soft skills (such as creating trust, negotiation and awareness), require some ethical sensibility. While in management the stakeholder view puts profit forward, for leadership in medicine special moral sensibility (which is also part of the medical tradition since the Hippocratic oath) plays a fundamental role: «Medicine is not a business, and the differences between it and a commercial enterprise are profound, although perhaps less well-defined in the current entrepreneurial climate when compared to earlier times» [1]. As Ritchie has indeed highlighted, «Medical professionalism has been described as: 'A set of values, behaviors, and relationships that underpin the trust the public has in doctors'. For GPs, we must include our own core professional values [...] which form the basis of a moral covenant between GPs, patients, and society and, in turn, provide the foundation for effective leadership in general practice. While maintenance of professional values was once seen as the responsibility of individual doctors alone, I would argue that successful professionalism also vitally depends on the moral culture of the organizations in which we work» [11].

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[2] The NHS Leadership Academy in its webpage claims: «Why does leadership in the NHS need to change? Quite simply, because there's so much evidence connecting better leadership to better patient care. Francis, Berwick, Keogh point to it and so does leading academic, Michael West. They all make the link between good leadership and making a positive difference to patient care, care outcomes and the experience of care»; see https://www.leadershipacademy.nhs.uk/ retrieved 1.10.2017.

[3] This is actually what is being done in the Leadership in Medicine Altems Master provided by the Catholic University of the Sacred Heart since 2016.

[4] Levine and Boaks, for example, claim that the issue of the definition of leadership just what leadership is both central to the question of its relationship to ethics and it is problematic. It cannot be solved by either course of action taken by most authors namely either dismissing the question or answering it preemptively. But, nor can it be ignored. It must be answered in order to tell us what we need to know about the relationship between ethics and leadership and also to ground that answer [13].

[5] It is interesting to notice how change is advocated for the healthcare sector; according to Frenk et alii, «Health professionals have made huge contributions to health and socioeconomic development over the past century, but we cannot carry

out 21st century health reforms with outdated or inadequate competencies. The extraordinary pace of global change is stretching the knowledge, skills, and values of all health professions.

[6] Despite the tendency of the various professions to act in isolation from or even in competition with each other, i.e. the so called "tribalism of the professions": J. Frenk et alii, *Health professionals for a new century: transforming education to strengthen health Systems in an interdependent world* [6].

[7] Before Burns, leadership scholars were indeed ambiguous (or did not notice this point) regarding whether they were proposing a descriptive or a normative theory of leadership; this ambiguity led to a number of internal contradictions in much the same way as ambiguities between questions of ethics and law in normative reasoning lead to ethical and legal fallacies: J.B. Ciulla, *Leadership Ethics: Mapping the Territory and Id. Conversations and correspondence with Burns on the ethics of transforming leadership* [26; 28].

[8] Burns distinguishes between two main classes of values: modal and end values. Modal values include responsibility, fairness, honesty, and promise keeping. These rest on the values found in the means of an act. End values, on the opposite, include liberty, justice and equality. These enable leaders to turn their followers into leaders: J.B. Ciulla, *Leadership Ethics*… [26].

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Reseña

Review

Érick Pérez-Mora*

> *"Creo que harto más me cuesta digerir la idea de la muerte cuando estoy sano que cuando tengo fiebre".* (Montaigne)

Sacks, Oliver. *Gratitud.* Anagrama, México, pp. 2016-61.

Montaigne escribió que tener presente a la muerte constituye por sí mismo un acto para liberarse de ella; el ensayista agrega que "[…] el imaginarla con antelación supone sin duda una gran ventaja." (Montaigne 2010, 130). Como médico que era, Oliver Sacks no tenía problema con hacer dicho ejercicio. Los médicos siempre están cerca de la muerte.[1] Pero no sólo la imaginan, sino que frecuentan con ella en su día a día: la combaten y –en otro casos– tratan de reconfortar a sus pacientes para afrontarla mejor.

En *Gratitud*, Sacks relata tres pasajes de su vida en que visualizó su propia muerte. El primero ocurrió cuando practicaba alpinismo, a los cuarenta y un años; entonces, recurrió a proporcionarse primeros auxilios. Relata brevemente esta experiencia en el primer ensayo del libro, que nos da una primera señal de su cercanía con la química desde su nombre: "Mercurio". También en "Mercurio", el autor transmite su inquietud ante la proximidad de su cumpleaños ochenta, pues el deterioro físico ha cobrado factura y la pérdida de personas cercanas a él está muy presente. En tercer lugar, "De

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Recibido el 30 de enero de 2019. Aceptado el 12 de febrero de 2019.

mi propia vida" es el texto a través del que comparte su sentir al ver *la muerte cara a cara* (p. 28). Lo escribió después de enterarse que padecía cáncer de hígado, secundario a una metástasis generada por un melanoma ocular que le había sido diagnosticado en 2005.

El autor expresa que los tres momentos estuvieron acompañados de retrospección sobre su vida y, aún más, de amor por lo vivido. Por ello, podría colocar en la pluma del médico lo escrito por Etty Hillesum: "He saldado las cuentas con la vida" (Hillesum 2007, 118). He ahí la razón de su último ensayo, donde se descubre pensando en una tradición judía muy arraigada, a pesar de su alejamiento de la religión desde los dieciocho años. Me refiero al Sabbat: *cuando tienes la sensación de que tu obra está terminada y de que, con la conciencia tranquila, puedes descansar* (p. 61).

Sin haberse planteado ese objetivo, Sacks nos da su clave para lograr una vida plena que nos reconforte ante el desasosiego de la muerte: tener pasiones que disfrutemos hasta nuestro último día.

La natación fue una de ellas. La practicó desde que su padre lo llevó a tener "contacto con el agua antes de cumplir una semana" (Sacks 1997). Y lo siguió haciendo, aún después de enterarse de su metástasis, *cada día, pero más… lentamente* (p. 41).

Desde su primera década, *los elementos de la tabla periódica pasaron a ser mis compañeros* (p. 38), dice. Y empezó a relacionarlos con sus aniversarios *cuando* averiguó *lo que eran los números atómicos* (p.17).

También comprueba que no se equivocó de carrera, la medicina, porque se dio tiempo de *visitar pacientes* (p. 40) aún después de la embolización que le practicaron. Además, su trabajo como médico lo ayudó a superar la crisis personal que atravesó en la década de 1960.

Sus inicios en la escritura estuvieron ligados a la medicina, ya que, mediante la narración de las historias de sus pacientes del hospital Bronx, descubrió su vocación y se entregó *a ella en cuerpo y alma, con total determinación* (p. 54). Este libro es el reflejo más palpable: escribió hasta los días más cercanos a su partida.

No es coincidencia ver en las fotos –acompañando a los textos– a Oliver Sacks nadando, leyendo y escribiendo; así como una pequeña recopilación de objetos sobre una mesa, que (imagino) son parte de su colección de elementos químicos.

No sé si tuvo la oportunidad de morir bajo el *celestial resplandor* (p. 37), como lo quería; pero me reconforta saber que estaba rodeado*, igual que cuando era niño, de metales y minerales, pequeños emblemas de la eternidad* (p. 39).

El conjunto de ensayos que conforman esta obra fueron escritos y publicados en fechas distintas; pero la selección de los mismos logra la unidad temática sobre una preocupación no exclusiva de un médico, sino de todo hombre: la muerte. No es casualidad que el primer texto que vino a mi mente al leerlos fue *De cómo filosofar es aprender a morir*, de Montaigne, el ensayista de la condición humana. Confirmé la relación entre ambas obras al recorrer las páginas de *Gratitud*, donde supe que Sacks se acompañó de las enseñanzas que descubrió a través de la lectura de David Hume, *uno de mis filósofos favoritos* (p. 28), confiesa.

En todo momento, salta a la lectura la prosa que caracterizó a Sacks. Hay fluidez, producto –tal vez– de su habilidad en el agua; al fin, muchos de sus escritos se idearon mientras nadaba.[2] Tiene presencia la sensibilidad, que sólo puede ser resultado de las fuertes relaciones que cosechó. Y percibimos las referencias de un empático lector, tanto de las letras como de los hechos.

Para aquellos que no han leído a Sacks, *Gratitud* es una breve aproximación a su obra y permite vislumbrar la intensidad de su vida.[3] El libro es una oportunidad para acercarse a la escritura de quien bien Borges podría haber llamado el más literato de los médicos.[4] Mientras que para sus lectores recurrentes, Oliver nos deja en *Gratitud* una entrañable despedida.

El hombre cuyas plantas favoritas raramente eran los helechos[5] habrá de compartir las dos características por las que se maravilló con ellos:

> La belleza: "[…] son una forma de vida más simple pero tienen su belleza particular, una belleza muy delicada» (Sacks 2005), y la permanencia: "Son unos grandes supervivientes" (Sacks 2005).

La primera se refleja en su muy fructífera vida; la segunda es producto de su obra. Me da gusto ser cómplice en lograr dicha permanencia, que fue –a la vez– uno de sus deseos: *tan sólo albergo la esperanza de perdurar en el recuerdo de los amigos y de que algunos de mis libros puedan seguir* "*hablando*" *a la gente después de mi muerte* (p. 20).

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[1] En esto coincidiría conmigo, agregando a los militares, Svetlana Alexiévich.
[2] Su capacidad creadora bajo el agua la relata en "Nadar hasta morir".
[3] La descripción más profunda de su vida está en su libro *En Movimiento. Una vida*, publicado en español por Anagrama.
[4] Utilizo el adjetivo con el que Borges calificaba a Schopenhauer; en ese caso, como "el más literato de los filósofos". Dichas opiniones se encuentran en *Autobiographical*, donde además agrega que "Si hoy eligiera [yo, Borges]a un solo filósofo, lo elegiría a él [Schopenhauer]" (p. 29) [La traducción y los corchetes son míos].
[5] Sacks confesó su pasión por los helechos en la entrevista que le realizó Eduard Punset el 19 de enero de 2005.

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Review

Reseña

Érick Pérez-Mora*

"I believe that it is a lot more difficult for me to digest the ideas of death, when I am healthy, than when I have fever" (Montaigne)

Sacks, Oliver. *Gratitude.* Anagrama, México, pp. 2016-61.

Montaigne wrote that having death present, constitutes by itself, an act to break free from her; the essay writer adds that "[…] imagining it before hand, assumes without a doubt, a great advantage" (Montaigne 2010, 130). As a physician as he was, Oliver Sacks had no problem with doing such exercise. Physicians are always close to death.[1] However, they not only imagine it, but they frequently meet her in their day-by-day lives: they fight it, and –in other cases– they try to comfort their patients, in order to cope with it in the best way.

In *Gratitude,* Sacks describes three passages of his life, in which he visualized his own death. The first one happened when he was practicing mountaineering, when he was forty-one years old; then, he turned to provide himself with first aid. He briefly describes this experience in the first essay of the book, which gives us a first signal of his closeness with chemistry right from his name: "Mercury". Also in "Mercury", the author transmits his uneasiness

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Received on January 30, 2018. Accepted on February 12, 2019.

in face of the proximity of this eightieth birthday, because the physical deterioration has collected a toll and the loss –of people very close to him– is very much present. In third place, "Of my own life" is the text through which he shares his feelings when seeing death face to face (p.28). He wrote it after finding out that he had liver cancer, secondary to a metastasis generated by an ocular melanoma, which he had been diagnosed in 2005.

The author expresses that the three moments were accompanied by a retrospection on his life and, even more, for love for what had been lived. For that, he could place in the physician's pen, what was written by Etty Hillesum: "I have come to terms with life" (Hillesum 2007, 118). There lies the reason of his last essay, where he discovers himself thinking about a deep-rooted Jewish tradition, despite of his separation from the religion since he was eighteen years old. I am referring to the Sabbath: *when you have the feeling that your job is done and that, with a clean conscience, you can rest (p. 61)*

Without planning that objective, Sacks gives us his clue to achieve a plentiful life, which would comfort us in face of the emotional distress of death: to have passions that we would enjoy until our last day.

Swimming was one of them. He practiced it since his father took him to have "contact with water before even to be one week old" (Sacks 1997). He kept doing it even after finding out about his metastasis, every day but more… slowly (p.41).

Since his first decade, *the elements of the periodic chart, "became my companions" (*p.38), he said. Then, he started to relate them with his anniversaries, *when* he found out *what the atomic numbers where* (p.17).

He also verifies that he was not mistaken by choosing medicine as a career, because he took the time *to visit patients* (p. 40) even after the embolization that was performed on him. Furthermore, his work as a physician helped him to overcome the personal crisis he endured in the 1960's decade.

His beginnings in writing were linked to medicine; although, by means of the story telling about his patients at the Bronx hospital, he discovered his vocation and he rendered himself to it *in body and soul, with full determination* (p.54). This book is the most tangible mirror image: he wrote, up until the closest days to his departure.

It is not a coincidence, to see in the photographs –together with the texts– Oliver Sacks swimming, reading and writing; as well as, a small gathering of objects on a table, that (I imagine) are part of the collection of chemical elements.

I don't know if he had the chance to die under the *celestial glares* (p. 37), as he wanted; but it comforts me to know that he was surrounded, *the same as when he was a little child, of metals and minerals, small insignia of eternity* (p.39).

The set of essays, which form this piece of work, were written and published in different dates; but the selection of the same, achieves a theme unity over the worries not exclusive of a physician, but by every men: death. It is not by chance that the first text that came to my mind when reading them was about how to philosophize *is to learn to die,* by Montaigne, the essayist of the human condition. I confirmed the relationship between the two works by going through the pages of *Gratitude,* where I learned that Sacks was accompanied by the teachings he discovered through the reading of David Hume, *one of my favorite philosophers* (p.28), he confessed.

At every moment, it was evident when reading, the prose that characterized Sacks. It flows, as a product –maybe– of his ability in the water; after all, many of his writings were thought while he was swimming.[2] Sensitivity has presence that it can only be the result of the strong relationships that he gathered. We perceive the references of an emphatic reader, as of the letters as well as of the facts.

For those who have not read Sacks yet, *Gratitude* is a brief approximation to his work and allows visualizing the intensity of his life.[3] The book is an opportunity to get closer to the writing of whom Borges could have well called the greatest writer of all physicians,[4] while for his constant readers, Oliver leaves in *Gratitude* an endearing farewell.

The man, whose favorite plants were rarely the ferns,[5] would have had to share the two characteristics for which he had marveled with them:

> Beauty "[…] are a simple form of life, but they have their own beauty, a very delicate beauty" (Sacks 2005), and the survival: "They are great survivors" (Sacks 2005).

The first one is reflected in his very fruitful life; the second one is a product of his work. I am very glad to be an accomplice in achieving such permanence, which was –at the same time– one of his wishes: *I only have the expectation to endure in the memory of friends, an of that some of my books can remain «speaking» to people after my death (p.20).*

Bibliography references

[1] In this, I would concur with you, by adding the military, Svetlana Alexiévich.
[2] His creative capacity under the water is described in "To swim until death".
[3] The deepest description of his life is in his book "*In Movement. A life*", published in Spanish by Anagrama.
[4] I am using the adjective with which Borges used grade Schopenhauer; in this case, as "the greatest writer of the philosophers" such opinions are found in *Autobiographical*, where moreover he adds that "If I would choose [me, Borges] to a single philosopher, I would choose him [Schopenhauer]" (p. 29) [The translation and the brackets are mine].
[5] Sacks confessed his passion for the ferns in the interview made to him by Eduard Punset on January 19, 2005.

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[2] Montaigne, M. 2010. "How to philosophize is to learn to die". In: *Complete Essays*, 5th edition, 122-138. Madrid-España: Cátedra.
[3] Sacks, O. 1997. "Swim until Death". *Nexos*, August, available in: http://www.nexos.com.mx/?p=8456.
[4] Sacks, O. 2005, January 19. Interviewed by Punset, E., *Oliver Sacks or the complexity of the mind*, chapter 343, program Networks. Madrid: Rtve.

Reseña

Review

José Enrique Gómez Álvarez*

Netzahualcoyotl, Cruz. *Bioética y donación altruista de órganos. Aciertos y problemas*. Editorial Fontamara. Observatorio Mexicano de Bioética, México, 2014. 109 pp.

El libro, como apunta el propio título, aborda los límites del modelo altruista en la donación de órganos. Dicho de otro modo, «… el altruismo como único elemento regidor de los programas de donación, es una cuestión problemática» y «… el modelo de donación altruista en términos de equidad es desventajoso para la familia donante» (p. 17).

Para el logro de esos propósitos, la autora divide el tema en cuatro capítulos. El primero es la delimitación del problema (pp. 17-24). En él se plantea el carácter problemático de los trasplantes en el modelo de la total gratuidad sin ningún tipo de retribución por parte de los otros actores involucrados; es decir, la persona receptora y la institución de salud. En este capítulo se establece que entre los dos extremos de comercializar los órganos y el altruismo total, cabe una posición intermedia, que es recibir cierta retribución social y ética por la donación.

El capítulo segundo, «El altruismo como elemento regidor de la donación de órganos» (pp. 25- 43), se estudia, por una parte, el sig-

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Recibido el 30 de enero de 2019. Aceptado el 12 de febrero de 2019.

nificado e implicaciones del concepto de «altruismo» y, por otra, se presentan los resultados empíricos de un estudio de casos, en donde se muestran las complejas consecuencias en la familia cuando se realizan donaciones de personas vivas. El estudio empírico muestra muy bien las afectaciones psicológicas, costos económicos y sociales de ser donante. En particular, resalta la sensación de cosificación que perciben los sujetos involucrados al pasar por todo el protocolo que se centra en los aspectos clínicos básicamente. La autora no se queda sólo en el diagnóstico, sino que propone mejoras a ese proceso de donación, en donde se deba atender a los donadores con su nombre propio en todo el proceso, recibir atención psicológica, y absorber los gastos del proceso de donación entre otros. En conclusión: «atender la afección emocional y paliar en lo posible la afección económica –de los donadores- hace que toda una sociedad luche por evitar el consecuente impacto negativo en la cultura de donación que precariamente hemos logrado desarrollar» (p. 43).

En el siguiente capítulo, «Estudios cualitativos» (pp. 45-68), se estudian las consecuencias en las familias donantes del proceso de donación, pero ahora en donaciones cadavéricas. Se dio un seguimiento a seis familias donantes, de modo que se pudiera evaluar las implicaciones de la donación. El estudio demuestra que hay implicaciones psicológicas, económicas y sociales en los involucrados. Se dan implicaciones en el proceso de duelo debido a la dificultad de aceptar la muerte cerebral, y al mismo tiempo ver signos como la respiración o el latido cardiaco. Existen problemas entonces con el proceso del duelo y la aceptación de la donación.

Asimismo, el capítulo presenta otro estudio en población abierta acerca de la posibilidad de ser donadores. Se muestra que el hecho de descubrir que existen costos económicos en el mismo proceso de donación disminuye significativamente la posible aceptación de donar y tiene claras implicaciones éticas al no disponer de una información completa del proceso de la donación por lo que es: « …una trasgresión al principio de autonomía, beneficencia y no maleficencia… El protocolo de donación cadavérica debería establecer como punto de corte, el momento en que se determina que el paciente tiene muerte encefálica. A partir de ese momento, todos los gastos derivados –por cualquier concepto- deben ser considerado parte del protocolo de donación de órganos» (p. 67).

El siguiente capítulo, «Donación cadavérica en reciprocidad» (pp. 69-102), se centra ya en la propuesta central de todo el trabajo. Examina así las implicaciones filosóficas, jurídicas, médicas y sociales de la retribución recíproca de la donación. Asimismo, la autora no desdeña los posibles riesgos de esta perspectiva, como pudiera ser el convertir la reciprocidad en una «forma soterrada de compra-venta de órganos» (p. 92), la reciprocidad altruista que se convierta en egoísmo al atender la familia donante sólo sus intereses. La posible corrupción del mecanismo para así obtener beneficios sociales es otro peligro. El capítulo cierra con las conclusiones generales del estudio presentado.

Entre las conclusiones resalto la siguiente que va a ser un *leitmotiv* de todo el libro: «la propuesta de una donación cadavérica que no se base únicamente en el altruismo, surge de la necesidad que vemos de reestructurar los aspectos que ya están presentando problemas en el modelo de donación cadavérica altruista. En particular el aspecto económico, porque consideramos que el hecho de que la familia donante llega incluso a absorber parte de los gastos derivados del protocolo de donación, se debe a la tergiversación que el concepto de altruismo ha sufrido; es decir, altruismo se iguala a gratuidad… La familia donante puede ser altruista, pero eso no significa que esté dispuesta a absorber gastos» (p. 99).

En suma, la autora demuestra bien la complejidad en los protocolos de donación y las implicaciones en los donantes que, a veces, pasan desapercibidos. La investigación presentada es equilibrada y aunque algunos temas, como el de la justicia distributiva, por ejemplo, podrían ampliarse, logra muy bien lo que se propone.

El libro es un buen ejemplo de que hacer bioética no implica necesariamente sofisticadas elucubraciones conceptuales. Tiene el enorme mérito de hablar con claridad, argumentar con precisión equilibrar lo conceptual con los datos empíricos.

Review

Reseña

José Enrique Gómez Álvarez*

Netzahualcoyotl, Cruz. *Bioethics and Altruistic donation of organs. Successes and Problems.* Editorial Fontamara. Observatorio Mexicano de Bioética, México, 2014. 109 pp.

The book, as the title itself aims at, addresses the limits of the altruistic model in the donation of organs. In other words that «… altruism as the sole regulating element of the donation programs, is a problematic issue» and «… that the altruistic donation model in terms of equality is a disadvantage for the donor family» (p.17).

For the achievement of theses purposes, the author divides the topic in four chapters. The first one is the delimitation of the problem (pp. 17-24). In it, it is presented the problematic character of the transplants in the model of total gratuity, without any kind of retribution by the other actors involved, that is, the receptor person and the health institution. In the chapter, it is established that, between the two extremes of commercializing the organs, and total altruism, fits an intermediate position which is to receive certain social and ethic retribution, due to the donation.

In Chapter II. «Altruism as a regulating element of the organ donation» (pp.25-43) it is studied, on one part, the meaning and

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Received on January 30, 2018. Accepted on February 12, 2019.

implications of the concept of «altruism», and on the other hand the empiric results are shown that a study of cases where the complex consequences in the family when living people make donations, is shown. The empiric study shows very well the psychological consequences, and the social ones, of being a donor. Particularly it is highlighted the sensation of reification that the involved subjects perceive by passing through all the protocol which is centered in the clinical aspects. The author does not stay only in the diagnostics, but proposes improvements in that donation process, where the donors must be attended and taken care with their own name, through the whole process, to receive psychological advice, and absorb the expenses of the whole donation process, among others. In summary: «To take care of the emotional affliction, and ease as much as possible the economical impact of the donors, makes that all the society should fight to avoid the consequential negative impact in the culture of donation, that scarcely we have achieved to develop» (p.43)

In the next chapter «Qualitative Studies» (pp. 45-68), the consequences in the donor families from the process of donation are studied, but now in corpse's donations. Six donor families were given a follow-up, in a way that the implications of the donation could be assessed. The study shows that there are psychological, economic and social implications in the involved people. Implications are given in the mourning process, due to the difficulty to accept brain death, and at the same time see signs as the breathing or the cardiac beat. Then, there exist problems with the mourning process and the donor acceptance.

Similarly, the chapter presents another study to the open population, about the possibility to be donors. It is shown that the fact of discovering that there exist economic costs in the donation process itself, diminishes significantly the possibility of donor acceptance, and has clear ethical implications, by not having available a complete information of the donation process, for what it is:»… a transgression to the principle of autonomy, of beneficiency and no-maleficiency… The protocol for corpse donation should establish as a cut-off point, the moment it is determined and declared that the patient has brain death. Beginning at that moment, all the expenses incurred for any concept whatsoever, must be considered as a part of the protocol of organ donation» (p.67).

The following chapter «Corpse donation in reciprocity» (pp.69-102), focuses now in the central proposal of the entire job. Reviews this way the philosophical, legal, medical and social implications of the reciprocal retribution of the donation. Similarly, the author does not spurn the possible risks of this perspective, as it could be to convert the reciprocity into a «buried form of purchase- sale of organs» (p.62), meaning that the altruistic reciprocity, would be converted in selfishness, by the donor family, in attending and taking care only, of their own interests. The possible corruption of the process or mechanism, in order to obtain in this way, social benefits, is another danger. The chapter ends with the general conclusions of the presented study.

Among the conclusions, I want to highlight the next one, which is going to become the *leitmotiv* of the whole book: «The proposal of a corpse donation that will not only be based on altruism, emerges from the necessity we see of restructuring all the aspects that are already presenting problems, in the altruistic corpse donation model. Specially the economic aspect, because we consider that the fact that the donor family, also has to absorb and cover part of the expenses derived from the donation protocol, and it is due to the misrepresentation and distortion which the concept of altruism has suffered, that is to say, altruism is equated with gratuity… The donor family can be altruistic, but that does not mean for them to be ready to cover expenses». (p.99).

In summary, the author shows well the complexity in the donation protocols, and the implications affecting the donors, which sometimes, go unnoticed. The research presented is balanced, and even though some topics, such as the distributive justice, for example, could be enhanced, she achieves what she wanted to aim at.

The book is a good example of doing Bioethics, which not necessarily implies the use of sophisticated conceptual lucubrations. It has the great merit of speaking with clarity, discuss with precision, and balance the concepts with the empirical data.

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5. Diseña metodologías de investigación innovadoras.

Modalidad y horario:
Semipresencial, 5 fines de semana por semestre, viernes de 18:00 a 21:00 hrs. y sábado de 8:00 a 14:00 hrs. Las demás semanas del semestre son para investigación, estudio y preparación de actividades de aprendizaje vinculadas al proyecto de tesis.

Duración:
6 semestres.

PLAN DE ESTUDIOS

Primer Semestre:
- ⬛ Seminario de Antropología y Ética para la Bioética
- 🟧 Seminario de Metodología de Investigación Documental
- 🟩 Electiva 1

Segundo Semestre:
- 🟧 Seminario de Inicio y Final de la Vida
- 🟩 Seminario de Marco Teórico
- ⬛ Electiva 2

Tercer Semestre:
- 🟩 Seminario en Bioética Clínica y Consultoría
- 🟦 Seminario de Derecho y Bioética
- 🟧 Seminario de Protocolo de Tesis

Cuarto Semestre:
- 🟩 Seminario de Bioética Ambiental
- ⬛ Seminario de Argumentación en Bioética
- 🟧 Seminario de Métodos de Investigación Científica en temas de Bioética

Quinto Semestre:
- 🟧 Seminario de Investigación Avanzada I

Sexto Semestre:
- 🟧 Seminario de Investigación Avanzada II

ÁREAS ACADÉMICAS

🟧	🟩	⬛	🟦
Investigación	Bioética	Filosofía	Derecho

Inicio:
Agosto de 2019

Coordinación académica:
Dr. Felipe Vargas Mota
felipe.vargas@anahuac.mx

Facultad de
Bioética

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Reconocimiento de Validez Oficial de Estudios de la Secretaría de Educación Pública por Decreto Presidencial publicado en el *D.O.F.* el 26 de noviembre de 1982.