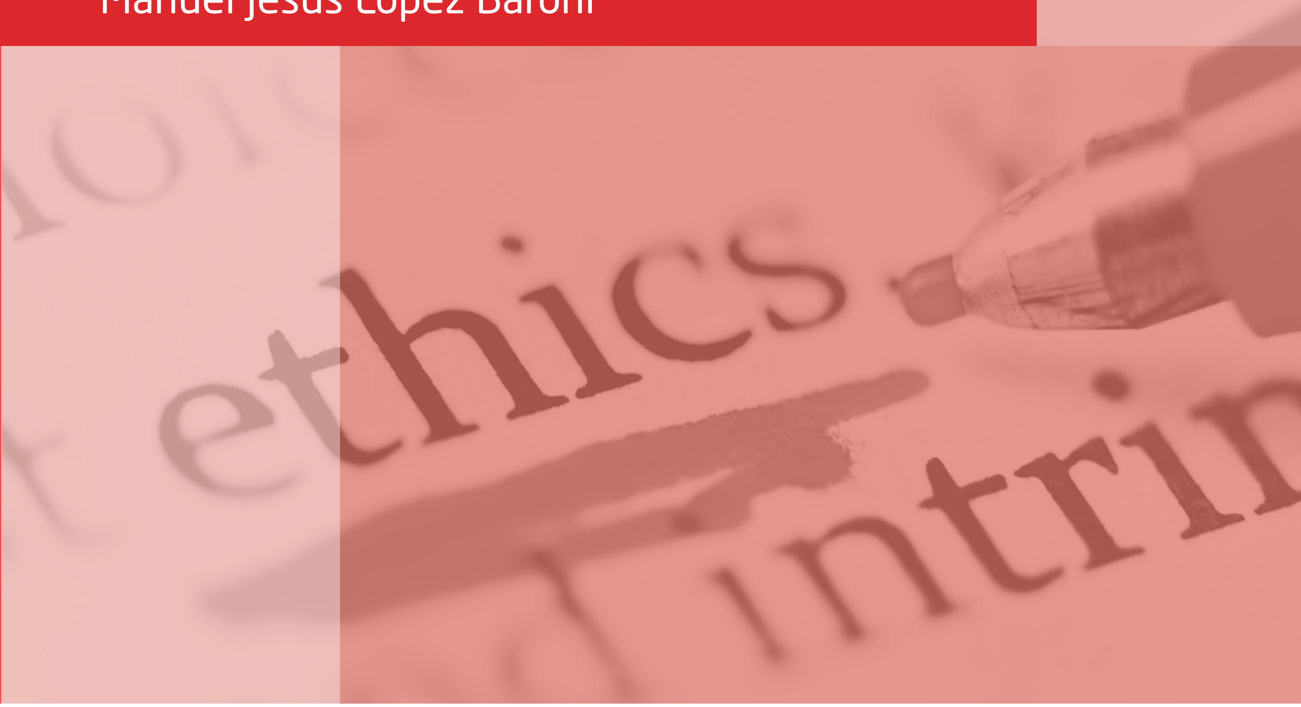
BIOETHICS COLLECTION

Handbook of Secular Bioethics (I)

Key Issues

María Casado
Manuel Jesús López Baroni



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Observatori de
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Universitat de Barcelona

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Introduction

This *Handbook of Secular Bioethics* is the result of many years of teaching and research. Thanks to this accumulated experience we are now able to summarize in this book the key issues of this new discipline. Bioethics, although initially questioned as a specific area of knowledge, has now consolidated its place in the study plans of most universities, in faculties of philosophy, law, biology, medicine and nursing, and in schools of engineering and other technical subjects.

The aim of this book is to provide the information that students on degree and post-graduate courses in the subject need, and our intention is to do so in a critical way, allowing readers to come to their own conclusions. We understand that university teaching must be addressed to providing a framework of knowledge and arguments to enable students to develop their own ideas and take part in the informed social debate, as well as to pass the subjects. This is precisely what would produce a high-quality democracy such as the one we would like to have. Obviously, what we have just said with reference to students also goes for anyone interested in bioethical issues, which by their very nature affect us and challenge us as citizens.

We the authors of this handbook are part of a powerful group with a strong identity. Our work is a continuation of the line that Doctor Casado began nearly 30 years ago in the Bioethics and Law Observatory (OBD, UNESCO Chair in Bioethics),[1] a research centre at the University of Barcelona that works in an interdisciplinary way and from secular points of view. Its presence can be felt both symbolically and practically, and nationally and internationally. Working online has made it possible to share knowledge with different international groups. Particularly, the creation of links to Latin America has en-

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[1] The OBD was created in 1995, and since 2007 it has been the home of the Chair of Bioethics that was awarded to Doctor Casado by UNESCO. It is part of UNESCO's UNITWIN Network for higher education, and of the eleven currently in existence in the world it is the only one in Spain. Our team was consolidated around the master's degree in Bioethics and Law, which was inaugurated in 1995 and has since then been taught uninterruptedly. More information at www.bioeticayderecho.ub.edu.

riched and reinforced discussion, something reflected in the group's networks, research projects and publications, especially *Revista Bioética y Derecho*, where the studies and analyses of many researchers from both sides of the Atlantic Ocean have converged.

For us, bioethics is an area of knowledge that requires plural approaches and solid scientific backup in order to analyse the ethical, legal and social consequences of biotechnology and biomedicine. By combining the words "law" and "bioethics" our goal is to allude not just to the legal system — which is used as a connecting thread when analysing problems — but to the idea that the human rights recognized in international texts constitute the lowest common denominator from a secular perspective. Our objective is to supply information, arguments and ideas to encourage autonomy and responsibility, so that bioethical decisions may result in the construction of a more transparent and democratic society.

The current development of bioethics as a framework of interdisciplinary thinking in order to face the challenges inherent in biomedicine and biotechnology has emerged in response to a set of ideas established over the years: from a religious angle, certain limits must not be transgressed, and human dignity is the last link of our civilization. From a secular, progressive point of view, progress must have repercussions for humanity as a whole, thus avoiding the profits being privatized and the risks being socialized; the emergence of new technology-based sources of power, each one more predatory, must be prevented; the market cannot resolve moral dilemmas, but at the same time progress must not be held back by dogmas and irrational beliefs; the figure of the entrepreneurial scientist differs from the idealized and naïve view that is transmitted about research activity; ethics is politics; law is ideology, and we have no external or past source to guide us or enlighten us in this unexpected and exponential technological progress that has taken place in recent decades.

The context of uncertainty about the future of science and technology explains why the problems of bioethics must be debated by society as a whole, the ultimate objective being to achieve the broadest possible consensus, an essential requirement for coexistence based on respect for democratic pluralism. The search for rules of the game that are acceptable to the majority of citizens, regardless of their ideological preferences, is not just the basis of the rule of law, but a precondition for the resolution of the countless problems that technological progress generates. Globalization has brought with it a different context for bioethics; today the main problems are no longer focused so much on patient autonomy as on justice, and disputes have as much to do with the impact of science and technology as with that of money. Neoliberal ideology has resulted in growing inequality in access to healthcare and to the benefits of research. The mechanisms of social protection have been minimized and the welfare state is being privatized.

The shift from patients to citizens that we were calling for has resulted in citizens being turned into consumers and, for that same reason, people, groups and populations are now more vulnerable than before.[2] In this time of runaway neoliberalism that promotes false freedom — because when individuals lack financial resources they are not free to choose — it is ever more necessary to appeal to solidarity and to the construction of values that can be shared.

In this respect, the law establishes minimums for coexistence and, precisely, the point of departure is respect for recognized human rights. However, do we have enough guarantees?

In our subject, the Council of Europe, as the body responsible for ensuring the acknowledgment and the effective protection of these rights, has attempted to offer a "common law" and to harmonize international laws in matters of bioethics, and it has also had an ad hoc committee to carry out this task. With its special dedication to the protection of human rights, it has drafted numerous resolutions on the rights of the sick, of the dying, on euthanasia, organ donation, transplants, AIDS, research with humans, assisted reproduction, genetic engineering and databanks, and it was responsible for drafting the European Convention on Human Rights in Medicine and Biotechnology, very important as a benchmark for both the continent and for non-European countries.

Along these same harmonizing lines, on 19 October 2005, in Paris, the UNESCO General Conference adopted the Universal Declaration on Bioethics and Human Rights, with the objective of guiding the international introduction of common principles for the whole of humanity with regard to ethical issues associated with medicine, life sciences and related technologies, taking into account their social, legal and environmental dimensions. It is the third regulatory text drafted and adopted by UNESCO on the subject of bioethics. The first was the Universal Declaration on the Human Genome and Human Rights, which the United Nations General Assembly adopted in 1997,

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[2] Recently, we have paid special attention to this subject in Casado (coord.) et al. (2015). *Bioética, derecho y sociedad*. Madrid: Trotta (first edition 1998); in Casado (coord.) (2009). Casado, M. (coord.). "Sobre la dignidad y los principios. Análisis de la Declaración Universal sobre Bioética y Derechos Humanos de la Unesco", *Civitas*; and in Casado, M. (coord.) (2016). *De la solidaridad al mercado. El cuerpo humano y el comercio biotecnológico.* Mexico City: Fontamara (new edition Edicions de la Universitat de Barcelona, 2017).

coinciding with the 50th anniversary, the following year, of the Universal Declaration of Human Rights; and the second was the International Declaration on Human Genetic Data, adopted in 2003 to establish the ethical principles that must prevail in the use of genetic data obtained from biological samples.

As far as Spain is concerned, there are a good number of laws addressed to contemporary bioethical issues, such as human assisted reproduction techniques, transplants, biomedical research and, above all, patient autonomy, which establishes a model for doctor/patient relationships based on the principle of informed consent and respect for the latter's autonomy.

Part of this legislation was inspired by the *Documents* drafted in the Bioethics and Law Observatory during the last 20 years, an inspiration that is in keeping with our idea that bioethics is not just an academic or clinical discipline, but that it must work to improve the society in which we live. We believe that bringing about changes in the law is one of the most effective means of influence, and this explains our public vocation and the Observatory's insistence on publishing rulings and reports openly with recommendations. It also explains the importance we attach to the legal and argumentational aspect of our teaching, aimed at preparing the students to change the reality in which they live.

With all this experience, persuaded that education is a basic cornerstone for having a truly democratic — free and responsible — citizenry, we have focused our efforts on teaching bioethics in different academic and professional areas. We are now taking things a step further by publishing this handbook. With it, we hope to provide knowledge of bioethics and its debates to everyone who is interested in the subject from a secular point of view.

From this perspective, we have produced this *Handbook of Secular Bioethics*, whose first volume includes the core and by now classic subjects of bioethics as an area of knowledge: its characteristics and specificities, its themes, its origins, the values, principles and rights in which it is framed, and the most important issues that the discipline deals with, from the beginning to the end of life, including sexual and reproductive health, voluntary termination of pregnancy, assisted reproduction, euthanasia, organ transplants and the environment. The issues raised by research, the new genetic technologies, biotechnologies, nanotechnology, artificial intelligence and big data, as well as citizens' rights in healthcare, the scope of conscientious objection and the role of ethics committees, will form the content, in the future, of a second volume.

The book can be used as a basis for teaching in universities, but it also makes autonomous learning possible given that it touches on the basic themes of the subject and after a careful reading of it readers will be equipped with the basic elements of information and debate. Combining brevity with thoroughness is a difficulty that we have faced in every subject dealt with in this handbook. While it is obvious that, due to the limited space available in a book such as this one, all aspects of every problem cannot be dealt with, our goal has been to systematically supply the most relevant information and arguments to enable each reader to consider them and to form opinions of their own. It is up to the readers to judge whether or not we have succeeded in this aim.

María Casado
Manuel Jesús López Baroni
Barcelona and Seville, summer 2018

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The Object of Bioethics

1. Introduction[1]

The term bioethics, although apparently consolidated, is problematic not just because of the scope conferred upon the name, but also because the problems with it are political and legal rather than ethical. The key issue focuses on whether or not it is necessary to regulate the possibilities that bio technologies offer us, and if so, in what sense. As they do not have a clear unambiguous social response, these problems result in a demand for legislation, and this becomes an issue that falls within the sphere of legal axiology: what are the values that we must protect and how should it be done? With regard to the possibility of intervening in biological processes, there is disagreement within society that generates conflict and this requires the law to play its part to establish the limits of the freedom of individual action.

Laws are evidently related to morals, although they do not depend on ethics for their configuration, and over the centuries the analysis of these relationships has been a crucial aspect of philosophical and legal thinking. Our approach starts from the confirmation of the moral pluralism of society, and that this pluralism is not just a fact but a constitutionally protected value. At the same time, however, we are opposed to scepticism in values, in the sense that we consider rational argument to be possible in ethics and that good reasons can be put forward in favour of the options that are chosen. Faced with the

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[1] This chapter revisits issues dealt with in Casado, M. (coord.) (1996). “La bioética”, in *Materiales de bioética y derecho.* Barcelona: Cedecs Editorial; Casado, M. (coord.) (1998). *Nuevo derecho para la nueva genética. Bioética, derecho y sociedad*. Madrid: Trotta. The second edition was published in 2015; Casado, M. (comp.) (2007). *Nuevos materiales de bioética y derecho*. Mexico City: Fontamara; Casado, M. (coord.) (2000). *Hacia una concepción flexible de la bioética. Estudios de bioética y derecho.* Valencia: Tirant lo Blanc; and in López Baroni, M. J. (2011). “Los principios no originarios de la Bioética”, in *Revista Argumentos de Razón Técnica,* no. 13, pp. 113-149; López Baroni, M. J. (2013): “Las Bioéticas Laicas”, in *Argumentos de Razón Técnica*, no. 16, pp. 121-161; López Baroni, M. J. (2013): “Ética y Moral en la Bioética”, in *Cuadernos Electrónicos de Filosofía del Derecho*, no. 27, pp. 96-120.

attitudes of extreme relativism, our initial standpoint here implies the possibility of rationally elucidating whether or not the moral judgments that we uphold are correct. In contrast to attitudes that preach the existence of absolute and incontrovertible truths, we propose that any moral judgment be subject to rational discussion and criticism.

Individual and social considerations can, moreover, be based on trust and faith in beneficent progress or radical mistrust of dehumanized science. The issues are often presented as conflicts of global attitudes. This is easy to see when dealing with euthanasia, abortion or the consideration of the limits of science. But these radical conflicts also arise in other fields — in political choices, for example, and we have learned to reconcile them, perhaps after centuries! These views of conflicts of absolutes, held by important philosophers and certain sectors of opinion, are not a good point of departure for analysing issues and learning to reconcile them, something we necessarily have to do. It is perhaps in this kind of situation where the tolerance of people and societies is best put to the test: tolerance as a tactic is not the same as tolerance as an attitude.

Many of the differences in the various meanings that are given to key terms, for instance “person”, “dignity” and “life”, besides placing us in an awkward position, could be a problem for starting the bioethical debate. Therefore, the first thing would be to discern their meaning and transmit these concerns to the citizens, since bioethical issues are also political issues.

This poses the problem of moral agreement, of consensus in ethics and its value. Is there disagreement in moral principles? In any case, can different views coexist? The discussion between universalist positions and those that stress diversity and pluralism is an absolutely topical issue. In our opinion, the main problem lies in the fact that ethics and the civil, or secular, moral discourse have not yet come up with solutions to the problems of bioethics. On the contrary, theology has dogmatic answers that are backed by centuries of unbroken usage. This leads us to the suitability of turning to the guidelines provided by human rights to frame these issues, while knowing how difficult it is to agree on them at the theoretical level of acknowledgment and of their basis (without going into the question of infringing them or observing them).

Indeed, one of the chief characteristics of the last 20 years is the proliferation of bioethics committees and analogous bodies in universities, research centres, countries and international bodies, in response to the unstoppable advance of biomedicine and biotechnology, to the need to tackle the challenges in a multidisciplinary way, and to the diversity of moral choices to deal with them. They include, for example, the Bioethics Committees of Spain, France, Portugal and Catalonia; the National Commission of Bioethics in Mexico; the National Commission of Biomedical Ethics in Argentina; the European Union's European Group on Ethics in Science and New Technologies (EGE); UNESCO's International Bioethics Committee, and the Nuffield Council on Bioethics in Great Britain. There have even been ad hoc meetings in Academies of Sciences to deal exclusively with bioethical issues, like the one held jointly by the National Academy of Sciences and the National Academy of Medicine in the USA, the Royal Society of London and the Chinese Academy of Sciences, in December 2015, to analyse the ethical implications of CRISPR genome editing technology. These committees and meetings are a direct consequence of what we were talking about, the plurality of moral standpoints and the need to agree on minimal universal rules.

Moreover, if we have to decide together what kind of human race we want to be and we do not come up with a common model, it may be positive and practical to start with the critique of *what we do not want to be*. In this respect, Lucien Sève proposes, as the object of bioethics, the Kantian opposite: "Critique of Impure Reason", continually being transformed into experience. For this eminent member of the French National Ethics Committee (in which different moral families have coexisted for decades and have managed to reach agreements), the object of bioethics is to ensure respect, through technological innovations, for people. What do we mean by people and respect? What solution do we adopt with regard to the controversy over progress? Faced with the constant appearance of possible new developments we must think about the world we want. And so, after ethics we necessarily turn to politics.

2. The disciplinary specificity of bioethics

Based on the lines followed in recent decades, we consider that the specific characteristics that can be ascribed to bioethics, coinciding or not with other paradigms, are the following:

2.1. Interdisciplinarity

The majority of the problems analysed in bioethics transcend the traditional areas of knowledge and intersect different disciplines.

This characteristic means that no one can really master the innumerable ins and outs of our discipline, which moreover are growing continually. For this reason, the always longed-for overlap between the humanities and the sciences is more necessary than ever.

It could be argued that contemporary bioethics is rowing against the tide of the traditional system of university teaching. It is virtually unthinkable that students doing a Law degree should have to learn genetics, just as it is unheard of for a biologist or a doctor to tackle philosophical or legal questions. In bioethics just the opposite is the case. It is impossible to argue with any degree of rigour about a problem without taking into account knowledge that transcends what has previously been learned in any given speciality. Therefore, our discipline makes it necessary to maintain a respectful dialogue between specialists from different areas of knowledge, forcing us to listen to points of view that we have never previously considered within the narrow framework of our small circle of knowledge, always an unsettling exercise.

To sum up, dialogue, humility, respect and intellectual curiosity are essential contents of the bioethicist's bag. Otherwise, it will be difficult for us to confront a reality that is always advancing faster than our ability to assimilate and comprehend it.

2.2. Global nature

Although bioethics initially faced problems of a local nature in hospitals, which affected specific patients with their personal experiences and characteristics, the need was soon felt to establish rules that went beyond this framework, with the ultimate aim of achieving a lowest common denominator for increasingly larger groups. Thus, from the figure of the sick person with his or her particular case history we passed to that of groups affected by the same disease, and from there, to that of the citizens of a particular country. Now we aspire to place the rights and responsibilities of humanity on an equal footing with regard to biomedicine and biotechnology.

These pretensions to universality have been reinforced with the disturbing issues raised by technological advances, which force us to realize that the challenges of the present will affect the coming generations and all the other living beings that share this planet with us. Therefore, the greatest challenge for contemporary bioethics is perhaps to find the way to agree on rules, protocols and universal common minimums for all human beings.

2.3. Secularism

As we shall analyse later on, the neologism "bioethics" began life associated with the Catholic and protestant traditions, although for different reasons. For our part, we aspire to give bioethics a secular focus, respectful but at the same time critical of religions, far removed from faith-based dogmatic approaches as the only source of legitimation of values. Secularism in bioethics implies a political commitment to democracy, to the rule of law and to human rights as the ultimate limit of respect for the cultural plurality of mankind.

Tolerance, ecumenism, pluralism and intercultural dialogue have always been considered achievements from the perspective of religions, ideal situations that make coexistence between different spiritual worldviews possible. One example is the Tres Culturas Foundation in Andalusia, where, harking back to the past, Jews, Muslims and Christians come together. We demand our own space, a different vantage point, in the hope that we can deal with the numerous issues raised by bioethics from the perspective of atheism and materialism, with their limitations, which also exist, but without the debts generated by faith, dogma or the imposed hierarchy. This legitimates us to call for a debate without preconceived ideas and, therefore, on equal terms.

2.4. Pluralism

Secularism imposes a lowest common denominator for everyone, human rights, but at the same time it ensures a plural space, which makes it possible to confront the issues that our discipline tackles from different points of view.

From our perspective as teachers, respect for pluralism entails fostering the ability to give our discourses rigour and autonomy; to train people in the cut and thrust of argument and logic; to learn to clarify the numerous angles from which problems can be tackled, and lastly, to cultivate empathy for other points of view. The ultimate objective of the acquisition of these skills is to understand both the points in common with other worldviews and the substantial and unacceptable differences, something that can only be achieved through constant and uncompromising criticism, of our own attitudes as well. We cannot renounce the comfort of religious dogma to fall into other faith-based belief systems that could be equally, or even more, disturbing.

2.5. Possibilism

As we shall be discussing, in recent times the spread has been accentuated of hazy narratives that lack the necessary rigour when analysing problems in bioethics. Thus, on one hand, technophobic lines of argument are encouraged, which anathematize technology, science, and even reasoning itself. Pseudo-therapies and alternative thinking flourish everywhere and an idealization of a past as idyllic as it is imaginary is promoted in which human beings and nature coexisted in complete harmony. Esotericism would be the lower limit of bioethics.

At the other extreme we have techno-utopias. These narratives spread the idea that technology will overcome inequality and injustice, and they compete with religion by promising us that we can become immortal through illusory mechanisms of the regeneration and/or transfer of our consciousness to supports as imaginative as they are surrealistic. Naivety would be the upper limit of bioethics.

For our part, we aspire to situate the field of action of bioethics between the two extremes. We consider that bioethical reflection must accompany scientific progress, without stopping it or slowing it down, but at the same time we must be able to prevent or anticipate the scenarios that new forms of control, power, authority and injustice may represent. And all this without losing sight of the fact that some hypothetical future developments may endanger life as we know it, whereby it is necessary to realistically and carefully evaluate, without unnecessary alarmism but with Promethean naivety, the calls constantly coming from the scientists themselves.

Possibilism means, in this context, making the advance of science and technology possible, without in doing so renouncing consideration of the consequences, implications and far-reaching effects of this progress.

2.6. Social nature

We consider that one of the objectives of bioethics must be for progress in biomedicine and biotechnology to have repercussions for society as a whole, avoiding monopolistic situations or the creation of new powers-that-be that exacerbate social inequality. The current preponderant neoliberal paradigm aims to privatize the benefits and collectivize the risks and losses. We aspire to reverse this approach, trying to minimize the risks and socialize the benefits. Not for nothing, what happens in the next decades with new technologies will affect the future of our planet.

In sum, interdisciplinarity, pluralism, a global and social nature, scientific possibilism and secularism will be the signs of identity of bioethics from our point of view.

3. THE MAIN THEMATIC AREAS OF BIOETHICS

What are the main thematic areas of our discipline? Despite the fact that it would be easier for us to list what does not constitute the subject matter of bioethics, we shall briefly list the most common thematic areas, without pretending to be exhaustive and even less so dogmatic about what it should or should not be. It is the issues and problems inherent in these thematic areas that guide our research and, consequently, the writing of this text.

1) *Clinical ethics.* Although this discipline, the preserve of medical personnel, appeared many years before bioethics, we consider that due to various vicissitudes that will be explained later on it has been absorbed by the latter, which has a broader scope. Moreover, the problems generated in medicine and nursing constituted the original core subject matter of bioethics until it transcended the clinical field, hence we pay it special attention. Transplants, sterilization, disabilities, drug addiction, sexuality, social stigmatization inherent in diseases like AIDS, patient autonomy, the specificity of healthcare legislation, these are all themes of bioethics.[2]
2) *The problems pertaining to the beginning and the end of life*. Thoughts on abortion and euthanasia especially, the bioethical themes that receive the most attention in the media, have on quite a few occasions served as the justification, the driving force or the stimulus for people to begin studying our discipline. Others related to them have arisen, such as assisted reproduction, embryonic stem-cell research, or surrogate motherhood, which rival them with regard to the capacity of scientific literature production and the glare of public attention.[3]

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[2] On these issues, we point out the following documents published by the Bioethics and Law Observatory: *Document on Oocyte Donation* (2001), *Document on the Refusal of Jehovah's Witnesses to Accept Blood Transfusions* (2005), *Document on Transplantation from Living Donor* (2011), and *Document on Bioethics and Disability* (2014).

[3] On these issues, we point out the following documents published by the Bioethics and Law Observatory: *Declaration on Embryo Research* (2001), *Document on Sexual and Reproductive Health in Adolescence* (2003), *Document on the Patient's Right to End His or Her Life Under Certain Circumstances: Declaration on Euthanasia* (2007), *Document on Conscientious Objection in Healthcare* (2008),

3) *The new genetic technologies*. Modern biotechnology began at virtually the same time as our discipline, in the 1970s. Nevertheless, the unusual acceleration of the progress made in this discipline has widened the range of themes, without anything leading us to suspect that it is going to stop. Of all of them, genome editing, in both humans and all other living beings, is perhaps the research that arouses most expectations and concerns. Thus, the sequencing of the human genome (*Human Genome Project-Read*), finalized in 2003; the project to synthesize this genome, begun in 2016 by George Church et al. (*Human Genome Project-Write, HGP-Write*); the uses of genetic information in itself (clinical forensic, etc.); the creation of genetically modified products and organisms, and others, are initiatives that demand a great capacity for understanding and foresight in our discipline.[4]
4) *The cognitive sciences*. Psychiatry, psychology, philosophy of the mind, and neuroethics have gradually been incorporated into bioethics. The requirements of these disciplines may even end up creating their own separate ethics that autonomously confronts the specificities of its study subject, such as the brain, the mind and human behaviour. The techniques, invasive or not, for studying the brain, speculation about human free will, the ultimate causes of human behaviour, the malleability of the brain, the diseases that afflict it, such as Alzheimer's or types of dementia, all generate a host of issues that make an interdisciplinary approach necessary. In fact, the achievements of the cognitive sciences are being very closely monitored by other disciplines, such as, among others, criminal law (how far are people accusable?); genetics (which genes explain our behaviour?); anthropology (how is the biological related to the cultural?); philosophy (what really is

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Document on the Voluntary Termination of Pregnancy (2016) and *Document on Ageing and Vulnerability.*

[4] Examining this issue in detail, the recent appearance of the CRISPR gene editing technique has profoundly changed our idea of what can and should be done, so we at the Bioethics and Law Observatory have paid it rapid and close attention. In 2016 we published a document entitled *Bioethics and Genome Editing in Human Beings*, and in July 2017 another collective article in the *Revista de Derecho y Genoma Humano*. In both documents we warned society of the enormous complexity of the situation generated by the appearance of this technique, of the need to create embryos specifically for research, something on the other hand prohibited by the European Convention on Bioethics; of the legislative disparity between China and the West; of the need to make it possible to use this technique for therapeutic purposes, the only limit being, for now, on the modification of the human germline; and of the permanent persistence of the atavism of human improvement, whose prohibition we ratify. The CRISPR technique also affects all other living species, whereby it is easy to infer that in the coming years it will be the subject of special attention.

human consciousness? To what extent are we free?), and ethology (what is the level of awareness, empathy or understanding of non-human living beings? Can we extrapolate them to human experience?).

5) *Nanotechnology, synthetic biology and artificial intelligence are extreme disciplines, as their study subject blurs the boundaries between living and inert matter.*[5] Regardless of the nature of these entities, living or not, the undeniable fact is that the challenges they pose affect the human race in a way hitherto unimaginable. Not for nothing, we could describe them, to paraphrase Ricoeur, as "disciplines of suspicion", and so they should also be studied.
6) *Big data*. The vast amount of information processed by computers, including the sequencing of the genome of living beings, raises many questions in reference to the level of privacy, data confidentiality, the spurious use of it, and so on. Moreover, the predictive capacity (data mining) of these databases extends to areas such as economics, health insurance, marketing and criminal law, and this compels us to establish protocols to avoid the ideological biases of the algorithms that are used in predictions. To give an example, a self-driving car will have to carry an ethical algorithm to decide whether it saves the life of the driver or a pedestrian crossing unexpectedly. Imagine that the car is able to consult a database with biographical information about the pedestrian and the driver in order to make a decision before impact.
7) *Environmentalism*. As we shall see later on, this subject was the focus of attention of some of the epigones of our discipline (Jahr, Potter), and although bioethics focused later on biomedicine it may be said that with the irruption of biotechnology, environmentalism has become one of the thematic cornerstones of bioethics. Moreover, our relationship with other living beings, and even more so with the environment, has varied substantially since we have been able to modify the genes of living beings. Environmentalism comprises a set of very complex issues in which clearly political parameters are mixed up with others, in theory less ideologically contaminated, such as those referring to health, the environment or the need to specify the moral status of non-human living beings. Others include genetically modified organisms and products; food sovereignty; the impact of nanotechnology on the environment and health; the monopolies of the multinationals; farmers'

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[5] On this issue, we point out the *Document on Nanotechnology and Global Bioethics*. Bioethics and Law Observatory (2010).

reactions to the new technologies; the way in which the signs of identity of so many cultures are being blurred by the impact of genetic modification; sustainable development; the dichotomy of organic agriculture versus industrial agriculture; the exponential increase of the human population; the finite nature of resources, and the use of animals for experiments.

8) *The issue of food*. Questions related to food have become more and more important in bioethics, to the extent that they are currently some of the most burning issues.[6] Food is on one hand associated with the huge challenge posed by reconciling limited planetary resources with the need to cover the nutritional needs of a constantly growing population, and on the other with clinical ethics and the problems that the new technologies generate when they affect food, and consequently, the health of the population. The challenges are therefore enormous.[7]
9) *Science and society*. In recent years studies have proliferated on the subject of the relationship between the scientific community and society, and on the social impact of the new technologies.[8] Civic participation, the scientific education of society, scientific fraud, the problems of authorship, the cultivation of values such as honesty, independence and impartiality in the scientific community, the social impact of research, accountability, the acquisition of competence in these subjects, the analysis of economic pressures, gender equality, open access, governance agreements, are all issues to be dealt with from the perspective that we are citing.

Along with these issues, others appear such as analysing the impact of the new technologies on society. Thus, for example, at MIT they handle scenarios with 80% unemployment due to technological progress, which raises doubts as to the feasibility of proposals such as taxing robots as if they were humans (surely robots are nothing more than algorithms), whether we should head towards a universal basic income in a society where only a mi-

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[6] The *Document on Food Information: Ethical, Legal and Policy Issues*, by the Bioethics and Law Observatory (2017) and the master's degree course Food Ethics and Law, directed by María José Plana and Itziar de Lecuona, in the context of this Observatory, meet the needs created by this issue.

[7] Plana Casado, María José (2018). *E-food control: challenges for the UE in the digital era / El control de los @limentos: retos para la UE en la era digital*. Doctoral thesis. University of Barcelona.

[8] Along these lines, in 2016 the Bioethics and Law Observatory promoted the *Declaration on Research Integrity in Responsible Research and Innovation*, in accordance with programmes such as *Science With and For Society* by the European Commission, or the RRI (Responsible Research and Innovation) policies, developed internationally by some members of our Observatory. Furthermore, in May 2018 the *Document on the Ethical Aspects of the Dialogue Between Science and Society* was presented, sponsored by the Bioethics and Law Observatory; and in January of that same year, the *Document on Ethics and Integrity in University Teaching.*

nority works, and how to share out the wealth generated by technological progress. With our minds focused on this perspective, we consider what new forms of discrimination will arise as a consequence of genetic engineering; for example, when it comes to gaining access to the jobs market, to health insurance, or even to finding a partner. We essentially try to assess, predict and anticipate what repercussions technologies will have on the social structures that form the backbone of human civilization, from the family to unemployment, including aspects such as birth, illness, reproduction, death, food, social ties, communication, or our identity as a species.

4. Definitions of bioethics

The number of definitions of this discipline greatly exceeds the space we are able to devote to them in a study such as this. For this reason, we will cite just three, representative of different perspectives:

Warren T. Reich, the compiler of the first bioethics dictionary, defined our discipline in the following way:

> Bioethics is the systematic study of the moral dimensions — including moral vision, decisions, behaviours, and policies — of the life sciences and healthcare, employing a variety of ethical methodologies in an interdisciplinary setting.[9]

The compilation of this dictionary, and the inclusion in 1974 of the entry "Bioethics" in the US Library of Congress, was an important step for the consolidation of the discipline, aside from other considerations that we shall look at in the next chapter.

María Casado, for her part, defines bioethics as follows:

> The analysis of the ethical, legal, social and political aspects of the impact of biomedicine and biotechnology, from a framework of respect and the promotion of the recognized human rights.[10]

As we can see, this definition implicitly advocates a secularist paradigm, since it uses, as a benchmark for values, the human rights recognized in the different international instruments that have been created in recent decades,

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[9] Reich, W. T. (ed.) (1995). *Encyclopedia of Bioethics*. New Jersey, 2nd ed.

[10] Casado, M. (1996). *La bioética. Materiales de Bioética y Derecho*. Barcelona: Cedecs, pp. 31-48.

and not religious beliefs. The term “impact” alludes to the practical, and not merely theoretical or academic, nature of our discipline, insofar as the proposed laws that are passed, after information and consensus *inter pares*, may finally be incorporated in a country’s legislation. This has happened with the documents drafted in the last 20 years by the University of Barcelona’s Bioethics and Law Observatory, which she directs and defines repeatedly as secular and multidisciplinary.

Lastly, Manuel López Baroni defines bioethics as:

> The *agora* in which specialists from different fields of knowledge communicate. Its themes are limited at one extreme by *political philosophy* and at the other by *science fiction*. Its object is the study of how human culture, that is, its *symbolic nature*, interacts with the laws of nature. It aspires to create universal axiological norms before it is *too late*.[11]

The definition alludes to the connections between bioethics, the traditional themes of political philosophy (justice, equality, freedom and democracy), and the hypothetical scenarios, at the limits of our imaginative capacity, which can be presented to us with, among others, the genetic modification of living beings, artificial intelligence, nanotechnology and synthetic biology. These future possibilities justify the need to create codes of values common to all mankind, despite the inherent difficulty of achieving workable agreements between such disparate worldviews, since the overlapping and reinforcement of the said disciplines could modify human civilization structurally and irreversibly.

5. Paradigms in bioethics

The implicitly ideological component of bioethics means that it can be examined from multiple perspectives. We are going to point out just three pairs of paradigms, each of which attempts to answer a question.

Indeed, if we analyse bioethics from the perspective of values, we have to compare the Anglo-American principlist model (Beauchamp and Childress) with that of the ethics of values, of Aristotelian/Mediterranean roots. This dichotomy attempts to solve the problem of what is the best way to lay the axi-

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[11] In López Baroni, M. (2015). *Bioética y Multiculturalismo: Políticas Públicas en España (1978-2013). El hecho cultural ante la revolución biotecnológica.* University of Barcelona, p. 559.

ological foundations of bioethics. If we focus on the degree of commercialization of the human body, we can contrast the Anglo-American model with the continental European one. And if we make theological and clerical militancy explicit — always underlying in certain themes — we have to contrast religious with secular bioethics, an antagonism that attempts to answer the question of how compatible are religious beliefs with atheist, agnostic or simply materialistic positions. We comment briefly on the three pairs of paradigms.

5.1. Principlism versus virtue ethics

Principlism is the name that, in the context of bioethics, is used to refer to the compilation of ethical principles (autonomy, justice, beneficence and nonmaleficence) made by Beauchamp and Childress in 1979. To understand the importance of this paradigm in our discipline one must start from two factors, the historical (three of those principles were already listed in the Belmont Report, as a result of the experiments carried out in the USA with Afro-Americans), and the religious (bioethics was for a long time simply a branch of Catholic theology). We comment briefly on these two factors.

Between the early 1930s and the 1970s, the American government carried out experiments with Afro-Americans in Tuskegee, Alabama, and it was recently discovered that they had also been carried out in Guatemala. Basically, these people were given placebos to cure their syphilis, despite the fact that from the 1940s it could be cured with penicillin. The results were published in scientific journals and were not questioned from the ethical point of view for four long decades.

In the late 1960s, in the context of Afro-Americans' fight for civil rights (by Dr Martin Luther King, Rosa Parks, and others), society began to question the legitimacy of such experiments. As a result of this being published in *The New York Times* (1972), the research was halted and a committee was created to specify the basic principles of research with human beings (1975-1978). The result was the Belmont Report (1979), in which the following principles were listed: respect for people, justice and beneficence.

Shortly afterwards, Beauchamp and Childress published a book in which they reiterated these principles,[12] with some variations, and extended them to

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[12] Beauchamp and Childress (1979). *Principles of Biomedical Ethics*. Several later new editions have been published which include the critiques that they formulated at the time.

biomedicine.[13] The success of this book is what leads us to the second factor mentioned, the religious. Thus:

> It cannot be denied that theologians played a prominent part in the early days of bioethics. Jonsen speaks of the "trinity of theologians" that "presided over the creation of bioethics": Joseph Fletcher, Richard A. McCormick, and Paul Ramsey. Other protagonists in the early years also came from theology, like James Gustafson, James Childress, Leroy Walters, George Kenoti, Warren T. Reich, William F. May, Robert Veatch and Jonsen himself. In Spain we ought to mention the work of, among others, Javier Gafo, Marciano Vidal, Eduardo López Azpitarte, Francisco Javier Elizari, Manuel Cuyás and Francesc Abel.[14]

The book from which we have taken the quote is subtitled *Theoretical Paradigms in Contemporary Bioethics*. Significantly, in it there is no reference to secularism, Marxism, or Latin American bioethics, where the problems, objectives and social concerns are very different.[15] And as can be seen, nor are there any women in this list of early parents of bioethics.

The reason for the disproportionate presence of theologians is simple: in bioethics they found an ideal neologism for fighting against their principal enemy, abortion. And this had nothing to do with clinical ethics (with centuries of tradition), or with biomedicine (in 1965, quite some time before Beauchamp and Childress's book, the World Medical Association formulated the Declaration of Helsinki, in which it listed the rules of action when researching with human beings).

As they maintain at the Borja Institute of Bioethics, belonging to the Jesuits, principlism represents "a notably elaborate effort to avoid relativism in the biomedical sphere and in clinical bioethics".[16] This is a euphemistic way of referring to those of us who are in favour of women being able to choose, of their own free will, whether or not to terminate their pregnancy; those of us who

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[13] The Belmont Report's respect for people was turned into the principle of autonomy; and, based on a list of four actions attributed by W. Frankena to the principle of beneficence (do no harm, prevent harm, eliminate harm and promote good), Beauchamp and Childress separated the first (do no harm) and made it the principle of nonmaleficence.

[14] Ferrer, José; Álvarez, Juan Carlos (2003). *Para fundamentar la bioética. Teorías y paradigmas teóricos en la bioética contemporánea*. Universidad Pontificia Comillas.

[15] There should be discussion about which field utilitarianism belongs to, in theory non-religious, especially when Beauchamp and Childress were in fact accused of practising "mitigated utilitarianism", which is another way of saying they were not dogmatic enough.

[16] Tubau, J.; Busquets, A. (2011). "Principios de Ética Biomédica", by Tom L. Beauchamp and James F. Childress. *Bioética & Debat*. Open platform of the Borja Institute of Bioethics.

believe that human beings can choose a dignified death with no external impositions, that research can be done with embryonic stem cells, with therapeutic cloning, with genome editing, and so on. And that the state and religion should be separate. Relativism, in this context, is synonymous with secularism, which includes the majority of feminist currents. Principlism is the paradigm that is opposed to it.

The success of Beauchamp and Childress's proposal is all the more surprising since, in fact, none of the four principles was formulated by them. The one about autonomy (the heart of law and morality, and the basis for responsibility), was already in the Nuremberg Code (1947), created as a result of the Nazis' experiments, and it links up with ideas about human freedom, thousands of years old. That of beneficence (basically, the obligation of medical staff to cure the sick) and that of nonmaleficence (not to cause undue harm) were part of the Hippocratic Oath. And the one about justice (the basic philosophical and legal principle) is lost in the mists of time, so much so that we cannot even date its origins.

And so, against principlism virtue ethics was proclaimed, based on the classic Aristotelian distinction between ethical virtues, alluding to habit (strength, self-control and justice) and intellectual ones (art, as knowledge of what is necessary; wisdom, as knowledge of necessary and universal things; practical wisdom; theoretical wisdom, and intelligence as the intuitive and direct reason for the first principles).[17]

The true importance of this claim does not lie in chauvinistic pan-European issues — in the Mediterranean, more than 2,000 years before American principlism emerged, people were already thinking about these questions — but in the defence of the welfare state (public health and education; the redistribution of wealth through a strong system of taxation, and so on), as opposed to the (more) capitalist model of the USA. There, private healthcare would be legitimized by the principle of autonomy: the patient is basically a customer, and the doctor/patient relationship is contractual. Therefore, the recovery of Aristotelian thinking is in fact part of a meta-debate about which model is the right one, not in biomedicine, but in politics.

This defence of the welfare state would actually be more appropriate for the European Union, or the countries of Scandinavia, than the Mediterranean countries proper (it could be said that we are still waiting to achieve this type

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[17] *Diccionario,* by Ferrater Mora. Entry "*dianoético*" (intellectual). I, p. 879, and V, pp. 3704-3705. RBA 2005. As Mora shows us, the distinction between ethical and intellectual virtues is not categorical, since caution, for example, "as practical wisdom, is considered by some authors to be an ethical virtue".

of state). However, for reasons not always easy to explain, Aristotelian-based virtue ethics is held up to be the alternative to the model of American private healthcare, represented by principlism.

5.2. The commercialization of the human body: the Anglo-American model versus the continental model

With reference to how acceptable the commercialization of the different parts of the human body is, we can distinguish two main models of thinking, the (European) continental and the Anglo-American.

Although the first paradigm, the continental, was initially dominant, centred on prohibiting and/or restricting the commercialization of the human body, it could be argued that it has gradually lost ground to the second paradigm, the Anglo-American.[18]

Indeed, in 2000, Hottois[19] clearly showed the existence of two opposing models that he called Euro-French and Anglo-American. Along the lines of the studies of the Council of Europe, he supported the priority of the first one, very much present then in continental European and Latin American bioethics: considering the human body off-limits to trade, based on the notion of human dignity, at the same time denouncing the European Union's mercantilist drift. This approach is opposed to abandoning the human body and its parts to their fate in a market dominated by money, technology and individual wishes. This would mean renouncing a long and valuable tradition based on the prohibition of the exploitation of the other, and on the consideration that the use by a third party of a part of the human body is the result of a gift, a voluntary act of solidarity.[20] Therefore it is the state — and not technology, the market or money — that should mediate in these exchanges, ensuring that agreements are transparent and that public order is observed at all times.

On the contrary, the Anglo-American approach is based on a certain interpretation of the ideas of Locke, as developed by libertarians who base them-

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[18] Casado, M. (2017). "Gratuidad o precio", in Casado, M. (coord.) (2016). *De la solidaridad al mercado. El cuerpo humano y el comercio biotecnológico.* Mexico City: Fontamara (new edition by Edicions de la Universitat de Barcelona, 2017).

[19] Hottois, G. H. (2001). "Corps humain", in Hottois, G. H.; Missa, N. *Nouvelle encyclopédie de bioéthique.* Brussels: De Boek Université, p. 243ff.

[20] Rodotà, S. (2010). *La vida y las reglas*. Madrid: Trotta, p. 139ff.

selves on the idea that individuals have inalienable rights and that private property is the most important of them. This axiom would also be valid for one's own body, which, thus appropriated, becomes an asset that can be the subject of free market exchange. This Anglo-American individualist tradition, and its contractualist idea of the practice of medicine, has eventually found its way into the mindset in our part of the world. Furthermore, individual freedom and wishes are mixed up and confused — frequently conditioned by the context of each — and they are elevated to the category of rights. As Rodotà argues:

> [...] the ideology of economic liberalism turns out to be the law of the strongest and social Darwinism, which has turned society into a market that — destroying social bonds and solidarity — abandons social cohesion to techno-structures frequently manipulated by private interests.[21]

To sum up, the regulation of trade in human body parts depends on how the body is perceived, as an object or as a subject, and it has a different meaning depending on every society's idea of the freedom and autonomy of the will, and of responsibility. If it is considered that the body is the subject's property, the limit of freedom is the possibility of the regeneration of the product, and information is required for valid consent. But if one starts from a relationship of identity between body and subject, even the separate parts of the human body deserve a different consideration that makes it necessary to take the notion of free status seriously. Of course, biomedical technologies have turned the human body and its constituent parts into raw materials for industry, but this must not involve a new source of discrimination and exploitation. Although it is not reasonable to think of a human body as the sum of its parts, nor is it desirable, conversely, to legally turn them into mere things. Perhaps it is right to establish specific regimes for products of human origin that, depending on their different symbolic natures, would not fit into a single concept either.[22]

At the start of this millennium it could still be argued that we had a choice of two paths. Now, it is clear that development has brought with it a tendency to the reification of the human body through technology and — even more

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[21] The contrast between these two tendencies that affects bio-law and bio-politics, closely related to bio-economics, has been outlined intriguingly by Hottois ("Corps humain"..., pp. 212-213), saying that an American citizen is the owner of his body, whereas the French citizen is merely the occupant of a body that belongs to the State.

[22] Hermitte, M. A. (2001). "Commercialisation du corps et de ses products." In: Hottois, G. H.; Missa, N. *Nouvelle encyclopédie de bioéthique.* Brussels: De Boek Université, p. 207ff .

so — the market, a divine entity that now regulates not only the economy but also human relationships and society itself.[23] A gradual change has been taking place in the model due to financial incitements, the education — persuasion — of advertising, or to a utilitarian rationalization of research itself and the idea of taking advantage of what is not used. An example of this is the reuse of the health data in the hands of the government by public/private third parties, and the establishment of presumed consent. It can be seen that the mercantilist approach to the human body — and to the law itself — is winning the game. It is obvious not just because of the proliferation of deplorable events that we read about every day, but also because of the philosophical foundations that, pragmatically, are shifting from facts to prescriptions. "It is" is turning into "it must be", and making an elementary naturalistic mistake.

5.3. Religious bioethics versus secular bioethics

Bioethics deals with issues such as the beginning and the end of life, in a context in which advances in biotechnology have gradually been increasing the number of living entities that deserve to be the subject of regulation. These include pre-embryos, clones, IPS cells and parthenogenesis. There are also more possibilities, for instance the genetic modification of living beings, including the germline, which affects not just the modified individuals, but the species to which they belong.

In response to the Catholic Church's attempt to monopolize the truth in these issues, more pluralistic analyses have emerged from secular, feminist and multicultural observatories. The irruption of Judaism and Islam in these debates has merely deepened this fracture. This however should be no obstacle to notable efforts being made to reach agreement on issues that affect both the coming generations and the future of the human race. We shall deal extensively with this clash of paradigms in the next chapter.

6. RECOMMENDED READING

Actes du Colloque International (2011). *Liberté de pensée et de recherche en Europe*. Commission Sciences de la Fédération National de la Libre Pensée.

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[23] Sandel, M. (2013). *Lo que el dinero no puede comprar: Los límites morales del mercado*. Barcelona: Debate.

Álvarez del Río, P. and Rivero Weber, P. (2009). *El desafío de la bioética*. Fondo de Cultura Económica (FCE).

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López de la Vieja, M. T. (2008). *Bioética y ciudadanía. Nuevas fronteras de la Ética*. Editorial Biblioteca Nueva, S.L.

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2

The Origins of Bioethics

1. INTRODUCTION[1]

The discussion about where and when bioethics came into being is not just academic or anecdotal. On the contrary, it is a question that must be considered in order to understand the subsequent development of the discipline and the subjects it covers.

The most usual criterion, almost unanimous, consists of associating the birth of the discipline with the person who "discovered" the neologism, and so the issue of the origins is reduced in practice to the search for the ancestral bioethicist, from whom the others are descended. This explains why Van Rensselaer Potter II, in 1970, and more recently Fritz Jahr appear in almost every handbook.

The limitations on this way of proceeding are obvious, since we are forced to ask ourselves what, then, is the status of clinical ethics, which has existed for centuries, or how to describe the thoughts on these subjects of non-Western peoples, who for obvious reasons were unable to discover the neologism because their languages are derived from a branch different to Greek and Latin. However, the main objection is that the fact that the creation, the discovery or the happy invention of the neologism "bio-ethics" was due to the religious concerns of those who gave birth to it is exalted.

In order to analyse this problem, where and when bioethics came into being, we shall use a model with two variables and four possible combinations. The two variables are origins of the neologism (the important thing is when the word bioethics first appears, regardless of the fact that the term has been rediscovered more than once over the years, or that the intentions of the creator did not coincide with contemporary bioethics); and origins of bioethics (the important thing is the group of subjects that are currently studied in the

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[1] This chapter is a partial summary of the book by LÓPEZ BARONI, M. J. (2016). *El origen de la bioética como problema*. Barcelona: Edicions de la Universitat de Barcelona.

discipline, essentially clinical ethics and the implications of biotechnology, irrespective of the term, word or neologism used). The interaction of these two variables generates four possible combinations, which we shall look at below.

2. MODELS FOR THE ORIGINS OF BIOETHICS[2]

2.1. "Origins of bioethics (1)" – "origins of the neologism (1)"

This is the official, most widely acknowledged criterion. Bioethics was born when Potter, an American protestant theologian, discovered the neologism bioethics in 1970, and it was reused shortly afterwards by the Jesuits in Georgetown when they created the Kennedy Institute. However, in the late 1990s it was announced that Fritz Jahr, a German Lutheran theologian, had beaten the Americans to it by publishing two articles with the word bioethics in almost half a century before Potter. This made it necessary to redefine this criterion, the attribution of the paternity of the discipline to the person who first invented the neologism.

To understand the haze surrounding the appearance of the term we shall use a strictly chronological order.

2.1.1. The resurrection of Fritz Jahr

A classic debate in our discipline has been the discussion about who actually created bioethics in the American cultural sphere, Potter or the Jesuits of Georgetown. In 1977, the German Rolf Löther publicly presented a compatriot of his, Fritz Jahr, as the true creator of the term bioethics (*bio-ethik*).[3] Jahr did indeed publish two articles in the magazine *Kosmos*, in 1927 and 1934, in which he used the neologism bioethics for the first time. In light of this criterion, this made him the first bioethicist.

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[2] We use a model with two variables and four combinations, similar to the one used by Gustavo Bueno in *¿Qué es la ciencia?* (Ediciones Pentalfa, 1995) and by Castilla del Pino in his *Teoría de los sentimientos* (Tusquets, 2000).

[3] IVA Y MUZUR, A. (2011). "Fritz Jahr: The Invention of Bioethics and Beyond." *Perspectives in Biology and Medicine*, vol. 54, no. 4, pp. 550-556.

This unexpected reappearance has generated discomfort in the USA, where they have more or less pretended not to notice, and jubilation in Europe, where Jahr has become an icon with whom to oppose American principlism. Nevertheless, we find it difficult to identity with the German's ideas.

Fritz Jahr was a Lutheran pastor who apparently never left his hometown, Halle, in the middle of Germany. The two articles that interest us are *Bioethics: Review of the Ethical Relationships of Humans to Animals and Plants* (1927) and *Three Studies of the Fifth Commandment* (1934). His work is essentially a reinterpretation of the Bible to adapt it to environmentalist thinking, using Kant and Luther as hermeneutists in order to do so. For Jahr, the first bioethicist was not really him but Saint Francis of Assisi, because of his love of animals.

Essentially, as we glean from his ideas, bioethics was a manifestation of pantheist mysticism, reminiscent of Romanticism (Herder, Wagner) and Protestant theology (Schleiermacher, Krause and Hartmann). The puritanism with regard to life and sex that imbues the two articles contrasts with his ideas about education, quite liberal for the time.

It should be pointed out that this manifestation of bioethics had nothing at all to do with human rights. As far as we know, Fritz Jahr was not a Nazi, but the fact is that he wrote absolutely nothing about the barbarity that characterized that period, not even after the Second World War (he died in 1953). The article in which he really detailed the content of his bioethics was published in 1934, one year after Hitler came to power. And the neologism bioethics corresponds to a context in which other authors were using similar expressions, such as *biopsychisch*.[4]

I believe that the chief result of the resurrection of Fritz Jahr is that it shows how sterile the debate about primacy in bioethics is. His concerns were purely religious, and it would be no surprise if one day we were to discover that the Nazis, who also had environmentalist concerns, as Luc Ferry denounced,[5] used the term for their propaganda. Hence it is not such a good idea to use Fritz Jahr to claim the European origins of bioethics as opposed to the American origins.

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[4] To be precise, Theodor Fechner and Rudolf Eiler. Salomé Lima, N. (2009). "Fritz Jahr y el Zeitgeist de la bioética", *Aesthethika, International Journal on Subjectivity, Politics and the Arts*, vol. 5 (1), pp. 4-11; Martin Sass, H. (2011). "El pensamiento bioético de Fritz Jahr, 1927-1934", *Aesthethika, Revista Internacional de Estudio e Investigación Interdisciplinaria sobre Subjetividad, Política y Arte*, vol. 6, no. 2, April, pp. 20-33.

[5] Ferry, L. (1994). *El Nuevo orden ecológico. El árbol, el animal y el hombre*, translation by Thomas Kauf. Barcelona: Tusquets, April edition.

2.1.2. Potter's environmentalism

Potter has been thought of as the father of bioethics for many years because in 1970 he published an article in which he used the neologism bioethics, which led everyone to mistakenly think that it was the first time this term had been used in the West.[6] The article was entitled *Bioethics: The Science of Survival.*[7] Although the appearance of Fritz Jahr has diminished his importance, Potter remains the first person to have published a book, *Bioethics, Bridge to the Future* (1971),[8] using this word.

There are several reasons why, over time, the Jesuits of Georgetown University eclipsed him: *a*) Potter attributed an environmentalist aspect to the term bioethics (just as, by the way, Fritz Jahr had done half a century earlier in Europe); *b*) the Jesuits of Georgetown developed bioethics around clinical ethics, a subject that had nothing to do with Potter's objectives and which, initially at least, had the support of the medical profession; *c*) Potter's book on bioethics is actually a series of 13 rambling articles that are totally unconnected,[9] whereby it could hardly constitute an exportable programme; *d*) the Jesuits had far more financial support.

The result of this unequal contest is that Potter on numerous occasions expressed his resentment over the Jesuits' conceptual theft, while on the Georgetown website Potter is not even acknowledged as the creator of the neologism. It could be said that the first American bioethicists unashamedly ignored one another.

Like Fritz Jahr, Potter was a Lutheran pastor, and therefore his idea of bioethics was also purely religious. Using Luther as his guide, he considered that the objective of our discipline had to be combatting the increase in the world's population. In his second book, he outlined an eight-point programme on bioethics in which he mixed ideas typical of religious puritanism (for example, encouraging marriage between virgins to avoid AIDS), with concerns typical only of the industrialized world.[10]

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[6] Potter, V. R. (1970). "Bioethics: The Science of Survival", *Perspectives in Biology and Medicine*.

[7] Ibid.

[8] Potter, V. R. (1971). *Bioethics: Bridge to the Future*, Englewood Cliffs, NJ: Prentice-Hall.

[9] Henk cites Reich's explanations about the scattered, digressive and inconclusive nature of Potter's work, especially his books in 1971 and 1988. Henk, A. M. J. (2012). "Potter's Notion of Bioethics", *Kennedy Institute of Ethics Journal*, vol. 22, no. 1, pp. 59-82.

[10] Potter, V. R. (1988). *Global Bioethics, Building on the Leopold Legacy*. East Lansing: Michigan State University Press.

The path Potter took is rather disconcerting. For reasons difficult to explain and perhaps too influenced by his follower Whitehouse,[11] he ended up embracing the ecology of the Norwegian philosopher Arne Naess. Thus, the deep bioethics of the last years of Potter's life is an imitation of Naess's deep ecology. Although Potter probably never seriously read the philosopher, the truth is that the Norwegian provided cover for an inflammatory form of environmentalism, which considers that there are millions of people too many in the world but does not explain what to do with the "surplus".[12] It is no surprise that the followers of Naess, to his regret, proposed to spread diseases in Africa to get rid of the excess millions. It was this kind of thinking that contaminated bioethics unnecessarily.

In sum, Potter is important because for almost 20 years the coining of the term was mistakenly attributed to him, which explains why he still appears in numerous handbooks, articles and studies as the father of bioethics.

2.1.3. The Jesuits' crusade against abortion

If the Jahr/Potter duo created the neologism, it was the Jesuits of Georgetown who really developed the discipline. Whether or not their objectives had anything to do with what we now call bioethics is another matter.

The intellectual father of this expansion was André Hellegers, flanked by Sargent Shriver and his wife Eunice Kennedy. Together, in 1971 they founded, at the Jesuit University of Georgetown, the Joseph and Rose Kennedy Center for the Study of Human Reproduction and Bioethics, funded by Eunice Kennedy, the late President John F. Kennedy's sister. To understand the true nature of this institute we have to go back to the 1960s, in the context of the Second Vatican Council.

In those years, with John XXIII as pope, a commission was created to study population, family and childbirth. This commission came at the same time as the Kennedy family's support for the studies of, among others, André Hellegers, on natural methods for controlling human fertility.[13] Hellegers was

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[11] Whitehouse, Peter J. (2003). "The Rebirth of Bioethics: Extending the Original Formulations of Van Rensselaer Potter". *The American Journal of Bioethics*, vol. 3, no. 4, pp. 26-31.

[12] Naess, A. (1973). "The Shallow and the Deep, Long-Range Ecology Movement. A Summary". *Inquiry*, 16, 1, 1973, pp. 95-100.

[13] Collins Harvey, J. (2004). "Andre Hellegers and Carroll House: Architect and Blueprint for the Kennedy Institute of Ethics". *Kennedy Institute of Ethics Journal*, 14, 2, June, pp. 199-206.

a member of the papal commission from 1963 to 1966, and he became its leading scientific figure.

In 1968, Pope Paul VI issued the encyclical *Humana Vitae*, a document of great importance for life and the struggle, in his words, against the two great evils of the time: divorce and abortion.[14] In 1969, André Hellegers, worried about the world's overpopulation, published an article in which he recommended non-westerners to use the withdrawal birth control method, which, as he said, the founding fathers of the American nation had practised so efficiently.[15] In March 1970, Hellegers published an article entitled "Fetal Development" in the Jesuits' magazine *Theological Studies*. The titles of all the other contributions make the editorial line crystal clear: fighting abortion.[16] Hellegers proposed that dilation and curettage should not be carried out on women, not even in cases of rape, because it might cause a miscarriage at a time when there was no way of knowing if a woman was pregnant in the first days of conception. According to some authors, Hellegers was partly responsible for spreading the Nazi myth that women who had been raped could not get pregnant.[17] In those years, Hellegers was a pro-life activist, and so he was often asked to appear in court as an expert, where he established woman/foˆetus, slaver/slave analogies to position himself against the termination of pregnancy.[18]

In 1969, the other bioethicist who is usually mentioned as the joint father of bioethics, Daniel Callahan, published a book with an introduction by André Hellegers entitled *The Catholic Case for Contraception*,[19] with texts by different theologians about natural contraceptive methods, written before and after the encyclical *Humana Vitae*. The only woman writing in it, Sidney Callahan, was the mother of the publisher Daniel Callahan's six children ("my pro-life wife")[20] and her chapter was entitled *Beyond Birth Control: The Christian Experience of Sex*, in which she analyses married life trying to make the

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[14] McCormick, R. A. (1979). "Theological Studies". *Moral Theology*, Mar 1, 1979, pp. 59-112.

[15] Hellegers, A. (1969). "Factors and Correctives in Population Expansion". *SAIS Review*, 13, 3, Spring, pp. 21-29.

[16] Various authors. *Theological Studies* (1970). Theological Faculties of the Society of Jesus in the United States, March, Volume 31, no. 1.

[17] Hildebrandt, S.; Seidelman, W.; Caplan, A. "Rape and Abortion: Negating a Myth". *Harvard Law, Bill of Health. Examining the Intersection of Law and Health Care, Biotech & Bioethics. A Blog by the Petrie-Flom Center and Friends*. At: http://blogs.law.harvard.edu/ billofhealth/2013/07/26/ rape-and-abortion-negating-a-myth/. Last visit, May 2014.

[18] Hellegers, A. (1975). "Abortion: Another Form of Birth Control". *Vita Humana*, no. 4, pp. 82-86.

[19] Callahan, D. (1969). *The Catholic Case for Contraception*. MacMillan Publishing Company, March.

[20] Callahan, D. (2012). *In Search of the Good: A Life in Bioethics*. Cambridge, MA, USA: MIT Press.

problem of contraceptive methods compatible with Christianity.[21] Daniel Callahan wrote the famous article "Bioethics as a Discipline",[22] which made it possible for the American Library of Congress to start using the neologism.[23]

In 1974, Hellegers published what might be the first bioethics handbook proper, *Problems for Bioethics. A Report to the Sacred Congregation on the Doctrine of the Faith*, his intellectual legacy.[24] The Congregation for the Doctrine of the Faith is the Catholic Church's modern name for the Inquisition.

In 1992, during the Democratic Party Convention, a joint letter was published in *The New York Times* defending Hellegers' legacy in his fight against abortion and publicly showing that there were anti-abortionists in the Democratic Party too. The letter was signed by Eunice Kennedy, her husband Sargent Shriver, the bioethicist Edmund D. Pellegrino, Sidney Callahan, the wife of the joint father of bioethics Daniel Callahan, Leon R. Kass, the future president of the neo-conservative American Bioethics Committee during the Bush era, and bodies and organizations such as Feminists for Life Law Project, Women Exploited By Abortion, National Women's Coalition for Life, and Evangelicals for Social Action. Two years earlier, Eunice Kennedy had publicly denounced the attempts to manipulate her brother's discourse in order to support abortion (*J. F. K. Would Have Defended Bishops' Right to Fight Abortion*).[25]

This is the context that explains the Joseph and Rose Kennedy Center for the Study of Human Reproduction and Bioethics, in Georgetown. Eunice Kennedy supplied the money needed to create an institute at a Jesuit university to study human procreation from the Catholic point of view. Ten days before the institute opened, the word bioethics was not in its name.[26] Several months before the institute began its activities, ethics as an area of reflection was not among its objectives.[27,28]

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[21] Guttmacher Institute (1970). "Catholics Speak Out". *Family Planning Perspectives*, vol. 2, no. 1, January.

[22] Reich, W. T. (1993). "How Bioethics Got Its Name". *Hastings Center Report*, November-December.

[23] Reich, T. (1994). "The Word 'Bioethics': Its Birth and the Legacies of those Who Shaped It". *Kennedy Institute of Ethics Journal*, vol. 4, no. 4, pp. 319-335.

[24] Beller, Fritz K. (1983). "Andre E. Hellegers as a Philosopher Portrayed by his Thinking. In Memoriam of an Admired Friend". *Europ. J. Obstet. Gynec. reprod. Biol*, no. 14, pp. 289-297.

[25] Kennedy Shriver, E. "J. F. K. Would Have Defended Bishops' Right to Fight Abortion". *The New York Times.* Available at*:* www.nytimes.com/1990/05/13/opinion/l-jfk-would-have-defended-bishops-right-to-fight-abortion-884290.html (last visit, May 2014).

[26] Friedman Ross, L. (2010). "Forty Years Later: The Scope of Bioethics Revisited". *Perspectives in Biology and Medicine*, vol. 53, no. 3, summer, pp. 452-457.

[27] Reich, T., *op. cit.*

[28] Ibid.

At some time before it began its activities, *Time* magazine cited the book that Potter had published with the neologism bioethics, and Shriver, Hellegers or people in their circles probably saw it. They considered that the word was appropriate for their objectives and they decided to incorporate it in the name of the Kennedy Institute that they were creating. The discussion about how it reached them has generated a huge amount of literature, but in reality the word bioethics was added to the institute's name purely by chance and because it was particularly euphonic.

What they were doing had nothing to do with what is now known as bioethics. The objective of those who founded the Kennedy Institute arose from the pro-life movements that in the 1970s positioned themselves against abortion. The ultimate aim of the people who created this institute was to indoctrinate healthcare staff so that they would not perform abortions, and to spread the word about the goodness of natural contraceptive methods. The contributions of women were in this case limited to those of the upper class, donating money and enlightening the working class and the ethnic minorities in the USA about what to do with their sexuality and their married life.

The clearly religious nature of early bioethics, militant, doctrinaire and evangelical, whether protestant, with Jahr and Potter, or Catholic, with the Jesuits, who turned it into a crusade, explains why the incorporation of new schools of thought in the discipline was not peaceable, let alone an invitation, but rather the consequence of a reaction against the attempts of pastors, priests and theologians to monopolize areas as sensitive as sexuality, reproduction and death.

2.2. "Origins of bioethics (1)" – "origins of the neologism (0)"

This model highlights the fact that our field of knowledge goes back thousands of years, as questions related to clinical ethics have been asked in all periods and cultures. The key lies in the fact that the term used for these reflections was not bioethics, but a different name that logically varied according to the place or the period.

This is why the model is expressed with the formula 1-0; our discipline has always existed, and it could even be said that it is inherent to human civilization, and the neologism bioethics is simply a name for something that existed before Potter and the Jesuits of Georgetown.

This explains why the debates, regarded as sterile, about who was the first to create the neologism, and the inherent process of beatification, are rejected in this model, considering it an exercise in naivety to place the birth of bioethics between 1970 and 1971. Having established this, the energies are focused on studying the different manifestations of the discipline that, with different names, have appeared throughout the history of humanity.

In our cultural context, this way of thinking has served to make a case for the existence of European bioethics, predating the American version; Mediterranean bioethics, enriched by the civilizations on the shores of that sea;[29] Latin American bioethics, focusing on its specific socioeconomic problems,[30] very different to those of the United States, and virtue ethics, originally Greek, as opposed to American principlism.[31,32]

In short, this model shuns the irredentism inherent in the supposed founding fathers of bioethics and, conversely, it understands our discipline as a process inherent to human civilization, which, with different names, concerns and solutions, has been with us ever since *Homo sapiens* appeared on the Earth.

2.3. "Origins of bioethics (0)" – "origins of the neologism (1)"

This model concedes that the neologism did indeed emerge in the American context (Potter, Georgetown, etc.), but it considers that the birth of bioethics proper came later, in the late 1980s and early 1990s, when schools of thought that had nothing to do with Christianity were incorporated in the discipline.

The core argument for justifying this standpoint is that it is considered that the 1970s bioethics of Potter, but especially that of Georgetown, had a strong religious, missionary bias, incompatible with the cultural and ideological plurality and diversity in the world.

There were two alternatives to the early concept of bioethics as a branch of theology: either giving ground — the neologism in this case — to the theologians, or on the contrary playing on the same field. This second option is what led numerous schools of thought to gradually enter bioethics, bringing new agendas, objectives and projects, but above all standing up to the purely reli-

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[29] Mallia, P. (2012). "Is there a Mediterranean bioethics?" *Med Health Care and Philos*, 15, pp. 419-429.

[30] Various authors. (2008). *Diccionario Latinoamericano de Bioética*. Organización de las Naciones Unidas para la Educación, la Ciencia y la Cultura (Unesco) and Universidad Nacional de Colombia; Casado, M.; Luna, F. (coords.) (2012). *Cuestiones de Bioética en y desde Latinoamérica.* Navarra: Civitas.

[31] Leone, S. (2012). "The features of a 'Mediterranean' Bioethics". *Med Health Care and Philos*, 15, pp. 431-436.

[32] Rodríguez del Pozo, P.; Fins, J. (2016). "Iberian Influences on Pan-American Bioethics: Bringing Don Quixote to Our Shores". *Cambridge Quarterly of Healthcare Ethics*, 15, pp. 225-238.

gious ideas of its early days. We can distinguish three major paradigms of thinking that have gradually drawn nearer to our discipline: feminist and secularist schools of thought and multiculturalism.

2.3.1. Feminism in bioethics

Theories about feminism predated the creation of the neologism bioethics and their objectives have run parallel to those of clinical ethics in the last two or three centuries, intertwining as their respective themes rubbed up against one another.

As we have seen, the founding fathers of bioethics tried to establish obligatory rules of behaviour in areas such as sexuality, reproduction, abortion and the family, so it was just a matter of time before they came up against the feminist paradigm. And this is indeed what happened.

Nevertheless, we should not talk of feminism in the singular, but of feminist schools of thought, plural, diverse, and still at odds with one another. Essentially, the axioms of feminism — Marxist, liberal, spiritual, both Western and Eastern, postmodern, psychoanalytical, and so on — provide a cluster of very diverse observatories on the themes of bioethics that have broken the monolithic mould of the early days. Another matter altogether, which I shall simply mention, is whether this same plurality of positions hinders the creation of universal and transcultural rules, something essential in the face of the progress made in biotechnology and biomedicine.

Despite the blurred conceptual boundaries between the different feminist schools of thought, we consider that their incorporation in bioethics has made it possible to synchronize the gradual process of women's equality with men, questioning the traditional concepts of marriage, family, sexuality, fatherhood and motherhood, based ultimately on the patriarchal order of early bioethics. This is how Silvia Tubert sees it:

> We should remember, once again, that male and female are not synonymous with man and woman. One thing is men and women as empirical entities, in a twofold sense: as beings naturally differentiated by their anatomical sexual characteristics, and as socially differentiated groups who are assigned and expected to perform certain (gender) roles. And something else altogether are male and female principles, which do not exist naturally and empirically, but which, as I mentioned earlier quoting Freud, are uncertain theoretical constructs. In other words, they are cultural creations that are offered to (or imposed on) subjects as

> ideal models that, in turn, are incorporated in particular individuals in the form of an ideal of the self.[33]

The results of this incorporation can be observed in the normalization of one-parent families, which has made it possible for women to be users of assisted reproduction techniques without the need for a male. They can also be seen in the recognition of the rights of transsexuals, which has questioned the classic male/female dichotomy and has made it necessary to acknowledge complex human plurality; in the legalization of same-sex marriage, with all that it entails as regards reproduction and the concept of family; and in the existence of an abortion law based on legal time limits, which has made it possible for women to exercise personal autonomy regardless of their cultural or religious affiliations. These achievements have also enabled the empowerment of women with fewer financial resources, as they have forced the public authorities to provide certain services across the board with regard to sexual and reproductive health.

In conclusion, the main objective of the incorporation of the different schools of feminism into bioethics has been the formal and material equality of women, lesbians, homosexuals and transsexuals with respect to the traditional archetype of the European Christian liberal model, the educated white middle-class male, the centre, nucleus and object of bioethics in its early days.

2.3.2. Secularism in bioethics

Essentially, secular bioethics shapes up as an alternative to plain bioethics. The reason for this distinction is the perception from materialist paradigms that since the beginning the discipline has been monopolized by religion, so much so that it is not necessary to place an adjective before bioethics to infer that the perspective is religious. Therefore, the expression "secular bioethics" implicitly denounces that this area of knowledge has been swallowed up by theologians, what Mori calls "the invasion of the field by Catholic culture",[34] whereby the defence of secularism would carry with it an attempt to decolonize and rebalance forces.

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[33] TUBERT, S. (1999). "Masculino/femenino; Maternidad/paternidad". *Hombres y mujeres. Subjetividad, salud y género*, compilation by M. A. González de Chávez, Universidad de Las Palmas, pp. 53-74.

[34] M. Mori's preface in the book by SCARPELLI, U. (1998). *Bioetica laica*. Baldini & Castoldi.

If we focus on the sociocultural level, we see that secular bioethics has been advocated with greater vehemence in the Latin world, something probably motivated by the disproportionate influence of the Catholic Church in those countries. This is why the most outstanding texts, like the two Italian manifestoes on secular bioethics,[35] Uberto Scarpelli's *Secular Bioethics*, Javier Sádaba's *Principles of Secular Bioethics*,[36] the book *What is Bioethics?,* by Gustavo Bueno,[37] or the documents published by the University of Barcelona's Bioethics and Law Observatory, directed by María Casado, have emerged in contexts strongly dominated, and not just in bioethics, by Catholicism. In this way, the commitment to secular bioethics would be part of decades of effort to separate the state from the Catholic Church, to mark the boundaries between the public and private spheres, and to solve the problem of "crypto-confessionality" (Puente Ojea) once and for all.[38] This would explain why Latin secular bioethics still seeks hand-to-hand combat with religion, while in the Anglo-American cultural sphere secular bioethics is full of infighting, as if the battle had already been won ages ago.

One of the founding fathers of the European Convention on Bioethics (1997), Marcelo Palacios, transferred this secular paradigm to bioethics in the following words: "With the previous foundations, in democratic, plural and free societies, in my opinion bioethics will be: 1) Civil, secular, without denominational determinants. 4) Humanistic."[39]

Thus, the expression secular ethics, although still ambiguous and elastic, given that it covers multiple ideological currents, would include the moral ideal of this approach. We could condense its characteristics into two aspirations, universalism and neutrality.

a) *Universalism*. This paradigm starts from the recognition of the existence of different moralities, one for each human community or group (ethnic group, religion, culture, etc.), but the aim is to achieve universal ethics that

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[35] Flamigni Massarenti, A.; Mori, M.; Petroni, A. (1996). *Manifesto di bioética laica*. Il Sole24Ore, 9 giugno; Mori, M.; Vattimo, G. et al. (2008). *Nuovo manifesto di bioetica laica.*

[36] Sádaba, J. (2014). *Principios de bioética laica.* Barcelona: Gedisa.

[37] Bueno, Gustavo, (1995). *¿Qué es la Bioética?* Oviedo: Pentalfa Ediciones.

[38] To understand what this term means in the Spanish context, it is essential to read the article by Puente Ojea "La llamada 'Transición a la Democracia' en España. Del confesionalismo al criptoconfesionalismo, una nueva forma de hegemonía de la Iglesia." In: Various authors (1994). *La influencia de la religión en la sociedad española.* Madrid: Libertarias/Prodhufi.

[39] Palacios, M. (1998). "Hacia el siglo de la Bioética". *Panorama actual de la bioética*. Encuentros de Filosofía en Gijón. Fundación Gustavo Bueno and Sociedad Internacional de Bioética, Gijón, 3 July, pp. 12-13.

transcend these particular moralities. The group of statements that represents these trans-moral values is called ethics, the equivalent of a kind of morality of morals.[40]

In this way, secular ethics would be a lowest common denominator for all human beings.[41] Below this LCD, human rights would be violated; above it would be the demands of the morals of each specific human group (religion, culture, etc.),[42] which would only bind the members of their respective particular moral communities.

Essentially, this idea of ethics represents the efforts of contemporary secularism, the heir in turn to the Western / liberal / enlightened / materialist tradition, to go beyond the world's moral multiplicity without in turn falling into ethnocentrism, at least in its strong version. Another matter is the ideological guideline that must be followed, namely, the question of neutrality.

b) *Neutrality.* Secular ethics aspires to be aseptic, neutral, non-ideological; in other words, it should not represent the values of any religion, culture, paradigm, etc. The degree of civic adhesion is achieved by accepting precisely that the values do not represent any human group in particular, but all of them.

In bioethics, this neutrality results in the defence of the rules that ensure the greatest number of options; for example, an abortion law based on legal time limits that does not oblige a woman to justify, publically or socially, her reasons for terminating her pregnancy, active euthanasia, artificial reproduction for single mothers, same-sex marriage, divorce, contraceptives, and so on. Secular ethics would offer a range of possibilities so that citizens may freely choose the option that is most in keeping with their religious and/or cultural convictions. The function of the state would not be to impose a single line for living life, but to allow the different alternatives to compete without being mutually exclusive. This would be the meaning of bioethics as "civil ethics" (Feito).[43]

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[40] López Baroni, M. J. (2013). "Ética y moral en la bioética". *Cuadernos Electrónicos de Filosofía del Derecho*, no. 27, pp. 96-120.

[41] Gómez Heras, J. M.ª (2005). "Repensar la bioética. Una disciplina joven ante nuevos retos y tareas." In: Gómez-Heras J.; Velayos Castelo, C. (eds.). *Bioética. Perspectivas emergentes y nuevos problemas.* Madrid: Tecnos, pp. 21-48.

[42] Peces-Barba Martínez, G. (2003). "Ética pública y ética privada." In: Tamayo, J. *Aportación de las religiones a una ética universal.* Cátedra de Teología y Ciencias de las Religiones Ignacio Ellacuría. Madrid: Dykinson SL, pp. 15-31.

[43] Feito Grande, L. (1997). "Panorama histórico de la bioética". *Moralia*, no. 20.

However, although secular ethics is neutral in the sense of not granting pre-eminence to any ideological or religious worldview, this does not imply that it is neutral in the sense of indifference. Therefore, on numerous occasions, and just as happens with feminism, this ethical paradigm collides head-on with multiculturalism. Its LCD is obligatory for all, regardless of the group they are in, which a priori makes it possible to judge the contents of the different groups' morals, or their laws, in accordance with this canon. Thus, from this premise it can be inferred that when the individual's interests clash with the signs of identity of their group, the individual's interests must prevail over those of the group (Kymlicka),[44] including the right of separation or re-instatement, which is not the same as banishment.

This explains why this participative neutrality (that is, ideological, as it is the heir to enlightened liberal tradition) takes as its canon of "ethicity" human rights as they are conceived in the West, headed by their paradigmatic text, the 1948 Universal Declaration of Human Rights (Casado).[45] This in practice makes it possible to compare, and where appropriate to condemn, the moral practices or the laws of different peoples, cultures or religions, even at the risk of committing ethnocentrism. It would in this case be a weak form of ethnocentrism, because any other option would turn the world into moral ghettoes, where each moral tribe would do as it pleased. In bioethics, the European Convention on Bioethics (1997) and UNESCO's Universal Declaration on Bioethics and Human Rights (2005) would include this spirit of non-indifferent neutrality with pretensions to universality.

The paradigm that inspires the University of Barcelona's Bioethics and Law Observatory is precisely the one I have just analysed, as can be read in its presentation:

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[44] Thus, Kymlicka, a classic of liberalism, upon analysing these questions, concludes that: "a) the rights of minorities should not allow one group to dominate other groups; b) nor should they allow a group to oppress its own members. In other words, liberals should try to ensure that there is equality among groups, as well as freedom and equality within groups." Kymlicka, W. (1996). *Ciudadanía multicultural.* Paidós Ibérica, p. 266.

[45] "Human rights constitute the legal foundations and, in turn, the inalienable ethical minimum, on which Western societies should be based. The previous statement is essential for establishing patterns of behaviour acceptable to everyone, regardless of the foundations on which it is based. [...] the point of reference of moral and legal attitudes is established on respect for human rights — as an ethical minimum and as a basis for the legal system — they seem the most appropriate nexus between different standpoints." Casado, M. (1998). "Nuevo derecho para la nueva bioética". *Bioética, derecho y sociedad.* Madrid: Trotta, p. 70. The second edition was published in 2015.

> The Bioethics and Law Observatory (OBD) is a University of Barcelona research centre that carries out its activity in an interdisciplinary way from secular points of view. Its members understand bioethics to be a field of knowledge that requires plural approaches and solid scientific backup in order to analyse the ethical, legal and social consequences of biotechnology and biomedicine. The objective is to supply arguments and proposals that encourage autonomy and responsibility, so that bioethical decisions will result in the construction of a more transparent and democratic society.[46]

The Observatory was created in 1994 with the intention of offering a non-denominational approach to our discipline. The following year the master's degree in Bioethics and Law was inaugurated. The word "Law" in the title alludes not only to the study subject, namely the legal system, but also to human rights as the ethical lowest common denominator from a secular point of view, a paradigm according to which in the last twenty years numerous professionals in different fields of knowledge have been trained.[47]

When the twentieth anniversaries of the Observatory and the Master's degree were celebrated, the retrospective analysis summarized in a few lines the new direction of bioethics:

> In those days bioethics was an incipient field of knowledge, which started from crypto-confessional approaches, advocated a principlist system close to indoctrination and was conducive to an *aggiornada* form of traditional medical ethics. When the Council of Europe (with its Convention on Human Rights and Biomedicine, of 1997) and UNESCO (with its three declarations on bioethical themes that culminated in the Universal Declaration on Bioethics and Human Rights, of 2005) endorsed our approach, it was easy for our ideas, which had previously been discussed acerbically, to be accepted by even their fiercest detractors.[48]

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[46] Presentation of the Bioethics and Law Observatory, at www.bioeticayderecho.ub.edu/es/presenta ción, last visit, December 2016.

[47] This perspective can be observed in the presentation of the master's degree: "The Master's degree is addressed to the training and qualification in bioethics of healthcare professionals, members of national ethics committees, research and healthcare committees, legal operators, judges, journalists, etc. and, in general, anyone interested in obtaining an overall, flexible and comprehensive view of bioethics, framed in the respect for internationally recognized Human Rights, and in obtaining an interdisciplinary education that allows for rational decision-making with regard to bioethical problems and issues", at www.bioeticayderecho.ub.edu/es/master, last visit, January 2016.

[48] Bioethics and Law Observatory, "XX Aniversario del Máster y del Observatorio de Bioética y Derecho de la Universitat de Barcelona. Barcelona", at www.bioeticayderecho.ub.edu/es/xx-aniversa rio#sthash.VskNF2Rk.dpuf, last visit, February 2016.

The importance of the Bioethics and Law Observatory is both symbolic and practical. On the one hand, its director, María Casado, obtained the UNESCO Chair in Bioethics in 2007, one of just nine in the world and the only one in Spain in this speciality, and on the other, the documents and reports drafted by the Observatory have been reflected in Spanish legislation, so much so that many of the laws passed in recent years have copied its proposals.[49] Moreover, the creation of links with Latin America has made it possible to enrich and reinforce the debates,[50] something reflected in the body's most emblematic publication, the *Bioethics and Law Journal*, where studies and analyses by numerous researchers from both sides of the Atlantic have appeared.

To sum up, the incorporation of secularism in bioethics has been the consequence of the militant, evangelical, colonizing ideas of early bioethics, monopolized by theologians. The basic axiom of secularism could be expressed by *etsi Deus non daretur* (as if there were no God),[51] which implies trying to lay the foundations of ethics and action without spiritual, religious or metaphysical elements.

2.3.3. Multiculturalism in bioethics

Lastly, multicultural trends were incorporated in bioethics in the 1990s. Between 1989 and 1991 Communism collapsed, whereby the logic of the Cold

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[49] CASADO, M.; LAMM, E. (coords.) (2011). *Reedición y análisis del impacto normativo de los documentos del Observatorio de Bioética y Derecho sobre salud reproductiva en la adolescencia y sobre la interrupción voluntaria del embarazo.* Bioethics and Law Observatory, Barcelona; CASADO, M.; ROYES, A. (2010). *Repercusión e impacto normativo de los documentos del Observatorio de Bioética y Derecho sobre las voluntades anticipadas y sobre la eutanasia.* Bioethics and Law Observatory, Barcelona; CASADO, M. (coord.) (2008). *Reedición y análisis del impacto normativo de los documentos del Observatorio de Bioética y Derecho sobre reproducción asistida*, Bioethics and Law Observatory, Barcelona.

[50] The networks created by the Observatory have also made it possible to contact professionals in different countries: "In some cases, the networks are coordinated by the OBD, as occurs with the Network on Bioethics and Human Rights (backed by the Generalitat de Catalunya), with the Bioethics Teaching Network (which was formed based on a European Union Alpha Project), of the Spanish Universities' Ethics Committees Network and other public research bodies, or coordinated jointly, as occurs in the Ibero-American Network — International Association of Bioethics (IAB). In other cases, the OBD is a member of other prestigious national and international networks, as is the case of the UNITWIN/UNESCO Chairs network, the Unesco.cat network, the network of the International Institute of Research in Ethics and Biomedicine (IIREB), and the European Association of Global Bioethics", at www.bioeticayderecho.ub.edu/es/redes, last visit, January 2016.

[51] Preface by Maurizio Mori in the book by SCARPELLI, Uberto (1998). *Bioetica laica*. Baldini & Castoldi, p. 14.

War, with its dichotomy of capitalism versus Marxism, gave way to globalization, with its melancholy heteronym, post-modernity, and the dichotomy between the Clash of Civilizations and the Alliance of Civilizations. The ideas that anthropologists had been working on for 200 years burst in on our discipline, filling it with concepts such as culture, civilization, ethnocentrism and relativism. The presence of multiculturalism in bioethics fractured along two lines of discourse.

In its first line, multiculturalism served to uphold the value of moral pluralism in a complex and diverse world. The Western principlism of early bioethics was questioned, as was, above all, the pre-eminence of the principle of autonomy, the badge of the paradigm of the white Anglo-Saxon Protestant and ultimately of the Western world. This questioning led to the defence of particularisms. Each people, tribe, culture, religion or civilization explained what *its* values were with regard to biomedicine, with the dialogical enrichment this entails, but with the handicap of redirecting the discipline towards a series of monologues with no possibility whatsoever of reaching across-the-board agreements.

In its second line of discourse, multiculturalism confronted the dangers of biotechnology, since, accompanying the cultural discourse, the scientific possibilities appeared in the 1990s. The collusion between computing, the Internet and biotechnology generated countless new concepts or expressions such as “embryonic stem cells”, “genetically modified products”, “therapeutic cloning”, “synthetic life”, “extinct species revival”, and others, which with great difficulty reflected the question marks hanging over the new reality. Ultimately, biotechnology aims to intervene, alter, control or dominate the genetic makeup of living beings, beginning with our species, or even to create new forms of life, artificial included. Hypothetical scenarios ceased to be the monopoly of science fiction and were here to stay. Multiculturalism had just been incorporated in our discipline when all of a sudden we had to consider how to regulate these scenarios with moral observatories as diverse as those existing on our planet.

Two alternatives thus emerged when it came to confronting the dangers of contemporary science. The first one attempts to mould the non-Western world according to the canon of human rights, which ultimately takes us back to the problem of Western / liberal / Euro-Christian / secular ethnocentrism (the rules that should govern biotechnology on a worldwide scale are *ours*). The second alternative consists in creating shared, transcultural, agreed values, without doubt a very aesthetic idea in theory, but actually rather impractical. It could be said that this is where we are now.

2.4. "Origins of bioethics (0)" – "origins of the neologism (0)"

The fourth model, a minority one but which does exist, considers that bioethics is not a serious field of knowledge, worthy of being taken into account, and that the neologism was a lucky invention useful for intentions that have nothing to do with thinking about or defending human rights in the sphere of biomedicine. The 0-0 formulation thus highlights the scant or zero importance of the two variables, "origins of the discipline" (which does not actually exist) and "origins of the neologism" (which has nothing to do with ethics).

Essentially, this view is put forward by those who question the legitimacy of bioethics as a discipline. For its defenders bioethics represents one or all of these axioms: *a*) the defence of American capitalist neoliberalism; *b*) the defence of a new form of colonialism, genetic and biotechnological; *c*) the replacement of the model of clinical ethics typical of doctors, based on beneficence, with an economistic model upheld by theologians, philosophers and intellectuals without full knowledge of it or representativeness; *d*) the legitimation of the abuses that continue to be perpetrated through an apparently benign discourse.

Although there are not many formal attacks against the discipline, we could mention, speaking for all of them, the book by Tom Koch and its intriguing title, *Thieves of Virtue: When Bioethics Stole Medicine*.[52]

3. RECOMMENDED READING

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3

Principles, Values and Citizens' Rights with Respect to Biomedicine and Biotechnology

1. INTRODUCTION[1]

When analysing the population's rights with respect to biomedicine and biotechnology, we must first bear some issues in mind.

On one hand, the rights, values and principles that we shall analyse succinctly belong to human beings in their capacity as citizens, and not just as patients. Indeed, the wide range of actions that may be generated as a consequence of biomedicine and biotechnology affect not just the people who need medical treatment, but, in general, any and all citizens, even when they do not have any direct connections to these disciplines. The protection of the environment, the genetic modification of living beings, uncontrolled experiments, attacks on generic rights such as privacy or collective health, among others, constrain humanity as a whole, the reason why the European Convention on Biomedicine is entitled "Convention for the Protection of Human Rights and the Dignity of the Human Being with Respect to the Applications of Biology and Medicine".[2] The same occurs with the Universal Declaration on Bioethics and Human Rights, adopted by UNESCO's General Conference in Paris on 19 December 2005. They are not texts designed solely and exclusively for patients, but for all human beings, regardless of how close their connections are to biology and medicine.

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[1] This chapter is part of the materials for the Bioethics and Law Observatory's master's degree in Bioethics and Law, and it was written by María Casado and Manuel Jesús López Baroni.

[2] Convention for the Protection of Human Rights and Dignity of the Human Being with Respect to the Application of Biology and Medicine, Oviedo, 4 April 1997. Ratified by Spain through an instrument of ratification, 23 July 1999. RCL 1999\2638. It came into force on 1 January 2000. From hereon, the European Convention on Bioethics. It was developed by the Council of Europe.

The European Union's Charter of Fundamental Rights was passed in Nice in 2000, symbolically and not legally binding for the countries of the European Union. Nevertheless, the European constitution included this charter in its articles, whereby, if it had been approved, its content would have had the same regulatory scope as the rest of the constitution. Since the constitution was not passed, the Treaty of Lisbon, of 2007, referred expressly to the charter, making it binding. For that reason, it is now a legal document of huge importance for all the countries of the European Union.

On the other hand, the sources of these rights are very diverse. Thus, we can find principles typical of bioethics (such as those listed in principlism, already mentioned): principles that came about in other contexts but which have been reused for our field of knowledge, like the principle of precaution or that of food sovereignty;[3] abstract values, such as dignity, at the limits of iusnaturalism or metaphysics; rights expressly acknowledged in some legal systems, such as active euthanasia; rights established in international documents, like UNESCO's European Convention on Bioethics and Human Rights, or article 3 of the European Union's Charter of Fundamental Rights;[4] rights only understandable in the light of the new technologies, like the right to be forgotten; pre-existing rights that gathered new momentum through the developments of big data and bio-computing, as in the case of the right to privacy and information that contains the genetic makeup of human beings, and so on.

Lastly, we must point out that responsibilities have also been created with regard to subjects or bodies that are unable to exercise the reciprocity inherent in any obligation, as is the case of future generations in issues referring to the protection of the environment, or of some animals, over which there are strict regulations when marketing products derived from their use by industry.

Upon analysing these rights and responsibilities, we are going to focus on a few values, rules and issues related to our subject, wholly irrespective of where they come from, citing the main national and international laws.

2. DIGNITY

Dignity has become unusually important with respect to progress in biotechnology and biomedicine. In the face of the importance attached to civil and political rights in liberalism, and to social, economic and cultural rights in socialism, the transverse nature of dignity could be upheld, since it cannot be exclusively attributed to either first- or second-generation rights. A good starting point for understanding what it means is Kant:

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[3] López Baroni, M. J. (2011). "Los principios no originarios de la Bioética." *Revista Argumentos de Razón Técnica,* no. 13, pp. 113-149.

[4] Thus, Directive 2003/15/EC of 27 February 2003, prohibiting the commercialization of cosmetics whose manufacturing entails experimentation with animals, came into effect in 2013. Regulation (EC) 1007/2009, of 16 September, prohibited the importation of products derived from seals. And Regulation (EC) no. 1523/2007, of the European Parliament and the Council, of 11 December, prohibited the importation and exportation of dog and cat fur and of products that contain it.

> In the kingdom of ends everything has either a price or a dignity. What has a price can be replaced by something else as its equivalent; what on the other hand is raised above all price and therefore admits of no equivalent has a dignity. […] What is related to general human inclinations and needs has a market price; that which, even without presupposing such a need, conforms with a certain taste, that is, with a delight in the mere purposeless play of our mental powers [an aesthetic object, for example, or an object that has great sentimental value for us], has a fancy price; but that which constitutes the condition under which alone something can be an end in itself has not merely a relative value, that is, a price, but an inner value, that is, dignity.[5]

The huge possibilities that contemporary technology offers have obliged us to consider what type of actions, experiments or investigations are compatible with human dignity. As Valls argues, "All humans have dignity, because we are all primarily and actively free, sovereign",[6] hence the need to reinforce human moral integrity. This may well be the reason, highlighting this value, which justifies the name of the European Convention on Bioethics: "Convention for the Protection of Human Rights and *Human Dignity* with Respect to the Applications of Biology and Medicine" (our italics).

Indeed, as we see, for the first time in an international document of this kind the title separates human rights from dignity, not because the latter does not pertain to them, but with the intention of stressing that the idea of dignity must come before all other values (such as sacrosanct "autonomy"). UNESCO's Declaration of Bioethics also uses this distinction, although in article 3, under the heading *Human Dignity and Human Rights*, where it establishes that: "Human dignity, human rights and fundamental freedoms must be fully respected."[7] In the case of the European Union's Charter of Fundamental Rights, instead of the term "dignity" it uses another with a similar meaning,

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[5] Kant. *Fundamentación de la metafísica de las costumbres.* (KW IV, pp. 434-435). Madrid: Santillana, 1996, p. 56, in Valls, *op. cit.* Worthy of mention is Valls' interpretation of the paragraphs by Kant referring to dignity in the article from which we have taken this citation: Valls, R. (2005). "El concepto de dignidad Humana". *Revista de Bioética y Derecho,* no. 5, December.

[6] Ibid.

[7] In this respect, the first part of the book *Sobre la dignidad y los principios. Análisis de la Declaración Universal sobre Bioética y Derechos Humanos de la Unesco*, by María Casado (2009), published by Civitas, at www. bioeticayderecho.ub.edu/es/solicitud/libro-sobre-la-dignidad-y-los-principios, deals with the concept of dignity from the different points of view upheld by the most important philosophers, jurists and bioethicists in our context.

"integrity", the heading for article 3 dedicated to the rights of Europeans with regard to medicine and biology.

In any case, the meaning in both documents, Convention and Charter, is the same. It is considered that certain actions are an attack on human dignity itself, regardless of the consent that those affected may give. In the case of the European Union, financial gain from the human body, eugenic practices and reproductive cloning are expressly prohibited, presupposing that these acts injure "human integrity", not in the physical but in the moral sense; in the European Convention on Bioethics (which pertains to the Council of Europe and not the European Union), we find similar proposals, although of greater significance, with the implicit intention that "human dignity" be respected.

To assess what this value represents in the recent history of bioethics, we must bear in mind that the famous experiments carried out on Afro-Americans in the USA (Tuskegee, Alabama) for almost 40 years, the basis of the Belmont Report, did not affect just the lack of consent (they were not informed that the treatments for syphilis they were being given were placebos and therefore useless), but their dignity as human beings, since these people were used as guinea pigs. The publication in scientific journals of the results of these medical actions, which were also performed in Guatemala, violated these people's right to not be objectified, that is, their right to not be treated as mere tools (as a means and not an end, as Kant would have it).

A second example took place in Pakistan, where the CIA put a certain doctor in charge of a false vaccination campaign. The ultimate aim was to fraudulently obtain the DNA of thousands of Pakistani children in the secret hope of locating the children of the famous terrorist Bin Laden, who, as we know, was eventually killed in Islamabad (although we do not know if he was found due to this campaign). The important thing about this practice is not that the consent of the children and their families was lacking; nor that they were deceived; nor that their DNA was sequenced massively; nor that it took advantage of the good faith of a population living in conditions of social and economic poverty; nor that, because of it, all kinds of vaccinations in that country were suspended, with the added risk of it being an area where polio is endemic and if mass vaccinations are not carried out this disease will never be eradicated from the face of the Earth:[8] no, the important thing is that the dignity of these people was violated, as they were used — Kant once again — as a means and not an end. This is the significance of this value here.

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[8] López Baroni, M. J. (2018). *Bioderecho y bioética durante la era Obama*. Aconcagua.

A third example has to do with human cloning. It is not prohibited because of a hypothetical evolutionary problem for the species (lack of genetic variability), or its potential use by totalitarian states (the cloning en masse of human beings), or at least this is not what concerns us here: reproductive (not therapeutic) cloning is prohibited because it is considered that it affects human dignity, a person's unique and unrepeatable nature. Although the individual is not just his or her genetic makeup but a group of subjective and irreplaceable experiences, it is considered that cloning a person, living or dead, harms their moral integrity. For this reason, article 11 of the Universal Declaration on the Human Genome and Human Rights, drafted by UNESCO in 1997, is formulated in these terms: "Practices that are contrary to human dignity, such as cloning for the purpose of reproducing human beings, must not be permitted."

The Protocol to the European Convention on Bioethics, of 1998, which also prohibits cloning, is even more specific: "For the purposes of this article, a human being that is 'genetically identical' to another human being is understood to be a human being who shares the same series of nuclear genes with another one."[9]

To sum up, two people are not identical because they share their genetic makeup (we only have to think of twins), but it is considered that cloning a person in a laboratory affects human specificity, namely, a person's singularity, even though the experiments cannot be duplicated in a test tube.

Lastly, the prohibition of the creation of interspecific hybrids, that is, the fertilization of an animal egg by a human sperm, or vice versa, or the creation of similar living entities, regardless of the fact that the resulting embryo may not be viable beyond a few days, is based precisely on this concept of human dignity. Although the transfer of animal organs, tissues or cells to a person is accepted, in the context of transplants, the creation of human chimeras is considered unacceptable.

This is the reason why the sentence by the Court of Justice of the European Union, of 18 October 2011, excluded from the patenting system "the procedures to create hybrids of living beings on a basis of germ or totipotent

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[9] Protocol of 12 January 1998, ratified by Instrument of 7 January 2000, RCL 2001\540, ratifying the additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (RCL 1999/2638, 2822), prohibiting the cloning of human beings, drafted in Paris on 12 January 1998. BOE 1 March 2001, no. 52, p. 7671.

cells of people and animals,"[10] not because they could give rise to science-fiction scenarios — therefore uncontrollable — but because it is considered that this kind of mixing violates the dignity of our species.

However, despite the fact that this could be considered the general rule, Spanish legislation allows these hybrids in certain cases. Article 14.4 of the first Law of Assisted Reproduction in this country authorized the hamster test to evaluate the fertilization capacity of human sperms (fertilization of a hamster egg with a human sperm up to the two-cell division phase [mitosis]). This same article allowed "other combinations" if they had the relevant administrative permission.[11]

Article 26.c.7 of the Law of Assisted Reproduction of 2006, currently in force, punishes as very serious conduct the creation of interspecific hybrids, but it allows them indirectly, by establishing the exception "in the cases of currently permitted trials". What is more, appendix B of the said law allows the creation of these hybrids not just with hamsters, but with "animal oocytes",[12] which massively increases the possibilities.

What we have just said shows that, although dignity is a fundamental value, its content is a long way from being sufficiently agreed upon. Some authors defend human reproductive cloning, stating that what makes human beings unique and unrepeatable are their experiences, not their genetic make-up; human chimeras are legal in Spain provided a certain period of development is not exceeded.

Moreover, we have to bear in mind that the word "dignity" is very often used spuriously, as a tool at the service of religious dogma. The Catholic Church, for example, holds up human dignity to oppose in vitro fertilization, therapeutic cloning, embryonic stem cell research, contraceptives, and, in general, any scientific progress in biomedicine that goes against its postulates. Across the Atlantic, the American Bioethics Committee during the Bush presidency, directed at that time by the Catholic theologian Edmund

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[10] Court of Justice of the European Union (Grand Chamber). Sentence of 18 October 2011. CJEU\2011\316.

[11] The actual wording is as follows: "The hamster test is authorized to evaluate the fertilization capacity of human sperms, until the stage when the hamster's fertilized egg divides into two cells, the moment when the test will be terminated. Other fertilizations between human and animal gametes are forbidden, except those with the permission of the relevant public authority, or where appropriate of the multidisciplinary National Commission if it has delegated powers", article 14.4 of Law 35/1988, of 24 November, of Assisted Reproduction Techniques.

[12] Specifically, the wording is as follows: B) Diagnostic procedures. Procedures aimed at evaluating the fertilization capacity of human sperms consisting in the fertilization of animal oocytes until the stage when the fertilized animal egg divides into two cells, the moment when the test must be terminated.

Pellegrino, published a document entitled *Human Dignity and Bioethics* to oppose en bloc any sort of scientific progress in biomedicine and biotechnology.[13]

Essentially, the American report was a reaction against the opinion of the philosopher Ruth Macklin, who dared to question the usefulness of the concept of "dignity" in contemporary bioethics.[14] Three-quarters of the authors of this report came, according to Pinker,[15] from the religious right, led by Leon Kass, the former president of the American Bioethics Committee and a well-known ultra-conservative thinker.

Dignity is therefore used as a euphemism to advocate the moral conservatism typical of the monotheist religions, with the paradoxical effect of defending, as in the case of the American neocons ("theocons"), neoliberalism and social Darwinism as options in keeping with human dignity.[16]

However, even if we sidestepped the religious discourses, the debate about the importance of dignity in bioethics would be no clearer. What is more, one could even speak of a dichotomy, dignity versus autonomy, among authors who take positions in secular, materialist or atheist observatories:

> […] dignity cannot be reduced to autonomy. This is, precisely, one of the core themes that can be found in several articles about dignity appearing in the book that María Casado coordinated some years ago: *Concerning Dignity and Principles: an Analysis of UNESCO's Universal Declaration on Bioethics and Human Rights*. In contrast to the ideas of authors such as Macklin, Pinker or Mosterín, who had suggested dispensing with the "intractable" concept of dignity and replacing it with that of autonomy (taking this to mean, approximately, the duty

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[13] Various authors, *Human Dignity and Bioethics. Essays Commissioned by the President's Council on Bioethics*. Washington, March 2008.

[14] Macklin, R. (2003). "Dignity is a Useless Concept." *BMJ* 327, pp. 1419-1420.

[15] To understand the content of the report, it is essential to read the article by Steven Pinker entitled "The Stupidity of Dignity: Conservative Bioethics' Latest, Most Dangerous Ploy". *The New Republic,* 28 May 2008.

[16] In any case, the defence of dignity in bioethics is recent, as Hottois' study showed: "Dignity has no place in principlism, the classic systematization of American bioethics. The first edition of the *Encyclopedia of Bioethics*, coordinated by W. T. Reich, has no entry for it and only indexes about ten frequencies. In 1995, the new edition of the *Encyclopedia* (in five volumes!) has no entry for it and it does not even appear in the index!" Another equally significant fact: the classic work of principlism — Beauchamp T. L.; Childress J. F. *Principles of Biomedical Ethics*, Oxford University Press, 1979 (1983, 2nd ed. enlarged) — mentions the term dignity twice, once to stress its vague nature, the second time within a citation: the index refers to "sanctity of life" (four mentions), and to "respect for persons" (seven mentions) (2nd edition). Hottois, G. (2009). "Dignidad humana y bioética. Un enfoque filosófico crítico". Translation by Chantal Aristizábal Tobler. *Revista Colombiana de Bioética,* vol. 4, no. 2, June-December, pp. 53-83.

> to respect the decisions of individuals, as long as they do not harm anyone else, at least), almost everybody writing this book on the subject of dignity argues that this view is a mistake, although they acknowledge that dignity is not exactly an easy concept to define and that, in some ways, dignity and autonomy are concepts necessarily linked to one another (Atienza).[17]

Thus, at one extreme we could cite the authors who consider dignity to be a metaphysical concept, hence they believe that this value must be replaced by the principle of autonomy, more quantifiable, understandable or verifiable from the point of view of legal positivism. From this perspective, iusnaturalism would be a myth, although a useful myth (Mosterín),[18] as one can only talk about rights from an anthropocentric perspective (there are no natural rights, but rights granted by one human being to another, without divine mediation).

At the other extreme, we could place the majority of those who collaborated in the abovementioned book, *Concerning Dignity and Principles: an Analysis of UNESCO's Universal Declaration on Bioethics and Human Rights.*[19] Even though iusnaturalists and positivists may be mixed up in this book to a different degree, these authors uphold the idea of dignity as a value in itself, separate from, although coordinated or at least compatible with, the principle of autonomy.

In conclusion, as a result of the exponential growth of biomedicine and biotechnology, the issue of human dignity has ceased to be a merely theoretical or abstract question and has gone straight to the forefront of the values to be upheld. It is, on one hand, a dam against not only cultural or religious practices — which no matter how ancestral or historical they may be do not have to be accepted — but also democracy itself,[20] under whose protection,

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[17] Atienza, M. (2016). "El derecho sobre el propio cuerpo y sus consecuencias." In: Casado, M. (coord.). *De la solidaridad al mercado. El cuerpo humano y el comercio biotecnológico*. Mexico City: Fontamara, pp. 33-61.

[18] Mosterín, J. (2014). *El triunfo de la compasión. Nuestra relación con los otros animales*. Alianza Editorial. p. 91.

[19] Casado, M. (2009).

[20] In line with, the predominance of dignity over autonomy, we would for example place the interpretation made by Ricardo García Manrique of article 12 of UNESCO's Universal Declaration on Bioethics and Human Rights, "human dignity must not be infringed through the invocation of considerations relative to cultural diversity and pluralism, whose importance is acknowledged by the Declaration (2009: 55-56,60)", which implies that dignity is a limit not just for individual but for collective autonomy, too: "In other words, dignity is a limit for democracy itself" (Atienza, *op. cit.,* 46).

in the form of populism, certain achievements may be threatened; on the other hand, it represents a danger when it is brandished by ultra-religious groups for the purpose of halting scientific investigation; lastly, it is an abstract concept that is hard to define, whose ultimate content must be specified case by case.

3. AUTONOMY

The principle of autonomy must be associated with the idea of individual human freedom and the Kantian maxim that every person is a moral subject, capable of universalizing their actions. It presupposes the ability of any human being to control their actions without outside interference. This principle is part of Beauchamp and Childress's principlism, and it may even be considered the most emblematic one, although, as we have already said, its existence cannot be explained by the ideas of these authors.

The first legal formulation of this principle can be found in the Nuremberg Code of 1947, drafted after the Second World War as a consequence of the Nazis' experiments in biomedicine. The second time it was included in an international text was in 1964, in the World Medical Association's Declaration of Helsinki (article 25).

The third occasion was in the Belmont Report, of 1979, the result of the commission that was created in the USA (1975-1978) to investigate the experiments carried out with Afro-Americans in Tuskegee, Alabama, for almost 40 years, although expressed as "respect for people". The fourth time we find a precise formulation of this principle is in the European Convention on Bioethics, in 1997.

Since 2000, the year this convention came into force in Spain, this principle has become an essential part of our legal system. What is more, we could argue that the application of this principle made it possible to replace a paternalistic model — the heir to the clerical view of Francoism in which decisions were taken not only by healthcare personnel but also by the powers-that-be or the Catholic Church, instead of by those directly affected — with another model based on autonomy, in which the patient becomes a fully entitled subject and makes decisions according to their convictions and beliefs.

Thus, different laws in the Spanish legal system, at both state and autonomous community level, have included this principle, especially Law 41/2002, of 14 November, regulating patient autonomy and rights and responsibilities in matters of information and clinical documentation, and Law 14/2007, of 3 July, of Biomedical Research.

The fifth occasion was in the Universal Declaration on Bioethics and Human Rights, of 2005, under the auspices of UNESCO (article 5).

Due to the large number of laws that include this subject, we shall just mention the most usual consequences of the principle of autonomy.

3.1. Informed consent

It is a person's right not to be subjected to any biomedical treatment, experimentation or research without their consent. We can compare how it is formulated by looking at different laws:

> *Art. 5 of the European Convention on Bioethics*
> An intervention in the field of healthcare may only be made after the person has given their free and informed consent.
>
> *Art. 3.a. of the Charter of Fundamental Rights of the European Union*
> In the context of medicine and biology the following will be respected, in particular:
> A) The free and informed consent of the person being treated, in accordance with the types established by law.
>
> *Art. 5 of UNESCO's Universal Declaration on Bioethics*
> The person's autonomy must be respected with regard to the power to take decisions, taking responsibility for them and respecting the autonomy of others.
>
> *Art. 2 of the Law of Patient Autonomy*
> 2. Any and all action in the field of healthcare generally requires the prior consent of the patients or users. This consent, which must be obtained after the patient is adequately informed, will be given in writing in the cases envisaged in the Law.
> 3. The patient or user is entitled to decide freely, after being suitably informed, between the available clinical options.
>
> *Art. 4 of the Law of Biomedical Research*
> 1. The free autonomy of people who may participate in biomedical research or who may contribute their biological samples to it will be respected, for which they will necessarily have previously given their express consent in writing after being suitably informed.

> The information will be given to people with disabilities in accessible conditions and formats appropriate to their needs.
>
> If the subject of the research is unable to write, consent can be given by any means offered by the law to allow them to state their wishes.

The requirement for express consent generates a huge amount of case law when people's autonomy is limited or non-existent. Nevertheless, the European Union's Charter of Fundamental Rights establishes no specific rules for these situations; and the clause established in article 5 of the Universal Declaration on Bioethics and Human Rights is too generic, as it simply says that "special measures will have to be taken to protect their rights and interests".

In this respect, only article 6 of the European Convention on Bioethics has specified this case law, although based on the general rule that it will only be possible to intervene in people lacking the ability to express consent when it is for their direct personal benefit.

The Convention authorizes certain medical interventions, for example inter vivos transplants of regenerative tissue, if specific requirements are met (which we shall examine in the corresponding chapter) and the incapable person is not openly opposed to it, and even some experiments, if the beneficiary is:

> […] the person affected or other people in the same age range or who suffer from the same disease or the same disorder, or who present the same characteristics. (Art. 17.2.i).

In this way, the use of people who are incapable of expressing their consent is avoided in experiments that benefit society as a whole, but not them or those who are in a situation similar to them.

Developing this possibility, the Law of Biomedical Research allows, in article 19, for experimentation with pregnant women, embryos or foetuses, provided that, besides meeting certain requirements, the research benefits them personally or pregnant women, embryos, foetuses or newborn babies as a whole; and in article 21, experimentation with people whose "emergency clinical situation" does not allow them to express consent. In these cases, the beneficiary of the research must be the person affected or others in the same situation. Moreover, among other requirements, the law demands that the Public Prosecutor be informed and that the consent of the person affected or their relatives be obtained whenever possible.

In the case of minors, the European Convention on Bioethics, in article 6.2, requires that the minor's degree of maturity, age and comprehension be properly assessed depending on the type of treatment, as well as collecting the express consent of their parents or representatives.

Respecting the content of the Convention, article 4 of the Spanish Law of Biomedical Research establishes that:

> 2. Consent shall be given by a representative when the person is legally incapacitated or is a minor, provided there are no other alternatives for the research. Consent through representation shall be given to the investigation to be carried out and shall be made respecting the person's dignity and for the benefit of their health.
>
> Incapacitated people and minors will participate as far as possible and according to their age and capacities in the decision-making throughout the research process.

On this point, we should point out that Spain prohibits inter vivos organ donation to minors, even though the parents may agree to it (we shall examine this in the corresponding chapter), and abortion used to be permitted for minors aged 16 or 17, even if the parents were opposed to it or did not know about it (the situation has changed, but we shall also analyse that later on).

In the event of a dispute between the parents and the minor the intervention of a third party may be necessary, which in the case of Spain means a court, without prejudice to the intervention of the Public Prosecutor to protect the interests of the minor. In certain situations, even though minors and parents agree, it may be necessary to notify the Public Prosecutor so that they are at least aware of this and may oppose it if they feel that the minor is being unjustifiably harmed.

A singular case in this subject is presumed consent in the context of transplants, a subject that we shall examine in the corresponding chapter.

Lastly, there are not usually any rules to specifically protect particularly vulnerable groups, such as people with very little money, the long-term unemployed, ethnic minorities, sick people (for example, a patient must not be led to believe that his or her medical treatment is going to be better or there will be more possibilities of survival or a cure if they voluntarily submit to a medical experiment), and so on.

3.2. The right to be informed of the consequences of medical treatment

Article 5 of the European Convention on Bioethics establishes that the person who is going to receive treatment in the field of healthcare:

> […] must be suitably informed beforehand of the purpose and the nature of the intervention, and of its risks and consequences.

The citizen is entitled to have the information adapted to his or her educational level or ethnic or linguistic group, with the ultimate aim of the affected person being able to fully understand the information. In this respect, articles 2 and 4 of the Law of Patient Autonomy establish the patient's right to be "suitably informed", which as a general rule must be done verbally, even though a note will made in the clinical record. This information must be offered "comprehensibly and suited to their needs", with the object of them understanding "at least, the purpose and the nature of each intervention, its dangers and consequences", which will allow them to make "decisions according to their own free will".

For its part, article 4 of the Law of Biomedical Research establishes that:

> The information will be provided in writing and will include the nature, importance, implications and risks involved in the research, in the terms laid down by this law.

Sometimes, the law demands that the information be especially detailed, as is the case with assisted reproduction:

> The information and guidance about these techniques, which must be given to those who wish to have recourse to them and to those who, where appropriate, are going to act as donors, will include their biological, legal and ethical aspects, and it must likewise specify the information relative to the financial conditions of the treatment. The medical teams performing these techniques in the hospitals and services authorized for their practice will be legally obliged to provide the said information in the proper conditions in order to facilitate its comprehension. (Art 3.3 of the Law of Human Assisted Reproduction Techniques, Law 14/2006, of 26 May).

3.3. The right to refuse treatment or withdraw consent at any time

The right to receive information, conversely, entails the possibility of refusing treatment after receiving it, or even withdrawing consent once it has been given, even though the patient may die as a result. Thus, article 6 of the European Convention on Bioethics states that: "The person affected may freely withdraw their consent at any time."

With the aim of providing healthcare personnel with legal certainty, article 4.2 of the Law of Patient Autonomy requires this refusal to be made in writing. And article 4, sections 3 and 4, of the Law of Biomedical Research, develops this right even further, in the context of experimentation in biomedicine:

> 3. The persons taking part in biomedical research may revoke their consent at any time, without prejudice to the limitations established by this law. The persons or bodies that have received this consent will take the necessary steps for the effective exercise of this right.
>
> 4. The lack of consent or the revocation of consent previously given will not affect the subject's healthcare attention in any way.

Among other implications, this right entails not only the possibility of ceasing to participate in an ongoing experiment, but also not transferring the embryos generated in a fertility treatment procedure already underway;[21] or not making an inter vivos organ donation even though consent was initially given.[22]

It is important to point out that the withdrawal of consent must not suppose a financial, equity or personal cost for the subject, although the law does not always expressly acknowledge that the said refusal will not affect the individual negatively.

Going into this issue in greater detail, in a document the University of Barcelona's Bioethics and Law Observatory dealt with the problem arising from reconciling the principle of autonomy, the right to life and religious freedom in

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[21] Article 3.5 of the Law of Human Assisted Reproduction Techniques, Law 14/2006, of 26 May, establishes that "the woman in receipt of these techniques may ask for their application to be suspended at any time during the process prior to embryonic transfer, and this request must be respected".

[22] Article 13 of the Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin, drafted in Strasbourg on 24 January 2002. Instrument of ratification by Spain. BOE no. 25 (Thursday, 29 January 2015).

reference to Jehovah's Witnesses, since this group refuses blood transfusions, which can have serious consequences for their health. The Observatory's recommendations were to respect this group's freedom to refuse transfusions, even though it could cost them their life (except when they are minors, in which case their right to life prevails and the courts may even be required to intervene), but that they should be consistent with this decision and should not demand alternative treatments that could be costly for the Treasury in a context of budgetary constraints.[23]

3.4. The right not to be informed (or the right not to know)

This right, which may seem paradoxical, can be explained because in certain cases a patient might not want to know what disease they have or how it is progressing, handing over the decision-making to the healthcare staff. In other cases, it may be that they do not wish to know their genetic information in case they are found to have a predisposition to an incurable disease.

The problem is that there may sometimes be third parties involved. Thus, if a person suffers from a contagious infectious disease, their health is a matter of public order, whereby their right not to know must be overruled by the right of the society in which they live to be protected. Moreover, a person's health condition may be shared unwittingly by the members of their family. And so, if it is discovered that an individual has a particular mutation that predisposes them to an illness, it is reasonable for their close relatives to receive that same information, so that they can take preventive steps if possible.

The right not to be informed is succinctly included in article 4 of the Law of Patient Autonomy, and, in greater detail, in article 4.5 of the Law of Biomedical Research, in the context of genetic information:

> Every person has the right to be informed of their genetic data and others of a personal nature that are obtained in the course of biomedical research, according to the terms in which they expressed their wish. The same right is acknowledged for a person who has contributed biological samples for the purpose indicated, or when other biological materials have been obtained from them.
>
> The person's right to decide not to be notified of the data referred to in the previous section, including any unexpected discoveries that may be made, will be

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[23] Martorell, M. V.; Sánchez-Urrutia, A. (coords.) (2005). *Declaration on the Refusal of Jehovah's Witnesses to Accept Blood Transfusions*. Bioethics and Law Observatory.

> respected. Notwithstanding this, when this information, in the opinion of the doctor in charge, is necessary to avoid serious harm to their health or that of their biological relatives, a close relative or a representative will be informed, after consultation with the medical committee if there is one. In any case, notification will be limited exclusively to the data necessary for these purposes.[24]

3.5. Consent through advance directives

Article 9 of the European Convention on Bioethics establishes that:

> Wishes expressed previously with respect to a medical intervention by a patient who is not in a position to express them at the time of the intervention will be taken into consideration.

Although the living will, or advance directives, will be examined in detail in the chapter referring to dignified death, we can say here that the function of this kind of document is to make up for the lack of ability to give consent in situations that are unlikely (for example, the request for a person not to be kept alive artificially), but no less deserving of attention.

4. Justice

Thoughts about the value "justice" usually pertain to the field of political philosophy, whereby they fall outside the scope of this study. We have selected some of the most common meanings of the term adopting it to the subject we are looking at. We will examine four of them:

4.1. "To each person, the same"

According to this formulation, everyone should receive the same amount, so an action would be just if no one receives more than anyone else.

Despite its apparent innocuousness, it is an axiom that basically corresponds to a liberal model, since it is based on formal equality. If we all receive

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[24] Although referring to confidentiality, it is interesting to point out that article 51.2 establishes that "in the event of genetic analyses of several members of a family the results will be filed and each of them will be informed individually".

the same, the possible differences between different groups are not taken into account (for example, ethnic minorities, underprivileged social classes, the discrimination of women as opposed to men, and so on).

Thus, this meaning of justice is useful for avoiding negative discrimination (everyone has the right to vote, for example), but it prevents positive discrimination (for example, gender quotas in a bioethics committee to prevent it from being made up of men only).

An example of the dreadful consequences of the literal application of this principle was the famous "baby cheque" during the term of office of President Zapatero's socialist government. Every woman who gave birth while this subsidy was in effect would receive 2,500 euros per year. On the face of it, it seems a just measure (every woman receives the same), but in practice it is absurd for a millionaire to receive the same help as someone who may be on the threshold of poverty. It was more reasonable to concentrate financial efforts on those who really needed it rather than share out the scant financial aid equally.

4.2. "To each according to his work"

This formula first appeared in the New Testament ("he who does not work, neither shall he eat", Saint Paul) and, by a paradox of history, it ended up in the Soviet Constitution of 1936:

> In the USSR work is a duty and a matter of honour for every able-bodied citizen, in accordance with the principle: "he who does not work, neither shall he eat." The principle applied in the USSR is that of socialism: "From each according to his ability; to each according to his work" (art. 12).

In the Marxist paradigm, this would be the criterion to follow during the existence of the socialist state, as a first step to its disappearance and entry in communist society.

Indeed, at this stage the state is still necessary (there are still capitalist states, so a socialist state is useful for upholding and spreading the achievements of the revolution). For that reason, some bourgeois reminiscences must still be maintained, such as everyone receiving according to what they bring to the revolution, according to their labour, and not according to their need.

If we transfer this idea to today's world, we can observe what criterion is followed for the pensions systems in economies in countries such as the USA.

Indeed, the retirement pension in a capitalization pension system (Spain's is for the moment, and with qualifications, a system based on sharing out the funds) implies that everyone receives according to what they contribute, so if they do not contribute anything, they receive no pension whatsoever.

The same is the case with private healthcare, which attends only to those who pay, regardless of social needs or other criteria of justice.

4.3. "From each according to his ability, to each according to his needs"

This principle was envisaged in the Marxist worldview for when capitalism had disappeared and all the countries in the world were socialist. At this stage, the socialist state would no longer be necessary and would be dissolved, giving rise to a society in which, without private property, police, army, laws, Church or bourgeois order, everyone would contribute what he could to the group according to his ability, but he would receive, not for what he contributed, but for what he really needed. Thus, a person could receive food, healthcare, and so on, even though he did not contribute with his strength to society, simply because his personal situation made him deserving of such attention.

Despite being an apparently utopian rule, envisaged for anarchist societies, it does in practice just about function in countries like Spain. In the Spanish public health system a person receives the treatment he needs (criterion of need) regardless of what he contributes in the form of social security payments or taxes (criterion of contribution).[25] A person earning a high income may be paying taxes and Social Security contributions for years without being given any healthcare attention if he does not need it. Conversely, a long-term unemployed person may receive the maximum possible medical care that the system can provide just because it is necessary.

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[25] The Spanish health service is funded through taxes, paid only by those who earn a certain amount of money. Moreover, the percentage that must be paid varies according to the income obtained (criterion of progressivity, not proportionality). Moreover, those who are paid a salary must pay a certain percentage applicable to their salary in Social Security payments, and so the amount also depends on the size of their salary.

4.4. "To each according to his worth"

The concept of worth in this context means market value. In a wholly neoliberal system, people's value is determined by the correlation between supply and demand, regardless of the (real) social value of a commodity or service.

This would explain why a state hospital's budget can be smaller than a top footballer's signing-on fee. Our society, which votes through the consumption of advertising and the election of politicians who satisfy its preferences, generally chooses (demands, prioritizes, etc.) the latter.

The priorities of biomedical research, for example, are very often established by the market, and not social needs. This means that research into rare diseases (they are not rare, they just affect a tiny minority), or research that is unprofitable, gets no attention whatsoever. The value of the research depends in these cases on the possibility of obtaining short-term gains, which conditions the market value of the research.

4.5. Justice as "social justice"[26]

The fifth meaning of this value establishes an antagonism between the principle of autonomy and that of justice, understood as social justice.

Indeed, from this perspective, the principle of autonomy is the key value in a market economy context where the patient, and in reality, the citizenry as a whole, acts as a customer. For this reason, their interaction with healthcare personnel has given rise to a contractual relationship, not too different to what is established with a bank when you take out a mortgage, or even to mere consumerism, where healthcare products are just like any other good or service.

According to Daniels's classic,[27] there are three main criteria for allocating healthcare resources: the market, rights and needs. For those who defend the first one, goods, including medical services, must be distributed according to supply and demand, because as individuals are the main actors in this model, they will seek the appropriate means to achieve their goals. The second model, which is enshrined in the Spanish Constitution, in the European Union and in many countries in our cultural ambit, comes up against the problem of cuts, the

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[26] Casado, M. (2016). "¿Gratuidad o precio? Sobre el cuerpo humano como recurso." In: Casado, María (coord.). *De la solidaridad al mercado. El cuerpo humano y el comercio biotecnológico*. Mexico City: Fontamara, pp.15-32.

[27] Daniels, N. (1995). *Just Health Care.* Cambridge: Cambridge University Press.

breakdown of economic and social rights in the face of the global crisis. The last criterion argues with regard to basic needs, about which there has been much debate in the spheres of philosophy, law and economics in recent decades. It has even been used as a basis for human rights, since if these needs are not met it is impossible for people to personally or socially achieve any purpose or goal in life.[28]

The economic crisis has provided the conditions for a rapid process of privatization of public services and an increase in inequality, and so countries, instead of protecting the citizens, give in to the private financial systems that govern the world's economy. In countries that had a good health service, like Spain for example, the increasing privatization of medicine is an attempt to appropriate public resources by private interests that notably increases inequality and erodes values, because commercialization — the market — corrupts certain values and practices, the core aspect of Sandel's ideas on this issue.[29]

The State must meet certain moral standards to enjoy legitimacy and hold coercive power; for this it must treat all its citizens with equal consideration — not just consideration.[30] Therefore, the gap between rich and poor — and the existence of extreme poverty — is indefensible and a market society must be rejected, as must a "night-watchman" state that simply guarantees transactions, and a state at the service of powerful private interests that dictate its rules. All this in a context of the commercialization of life, in which there seems to be no remedy for inequality and which is particularly ominous in matters of health.

5. PROHIBITION OF FINANCIAL GAIN FROM HUMAN BODY PARTS[31]

The national and international legal framework determines that transactions involving the human body and its parts should be free and based on solidarity. In principle, it could be said that, invoking human dignity, only things should have a price, whereby the human body and its component parts should be off-

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[28] Dieterlem. "Bioética y justicia distributiva." In: Casado, *op. cit., De la solidaridad*... pp. 365-367.

[29] Sandel (2013). *Lo que el dinero no puede comprar. Los límites morales del mercado.* Barcelona: Debate.

[30] Dworkin, R. (1996). *La democracia posible. Principios para un nuevo debate político.* Barcelona: Paidós.

[31] Casado, M. "¿Gratuidad o precio?...", *op. cit.*

limits to the market. But this point of departure, which is generally accepted, collides head-on with the reality of practices that are carried out in the sphere of health and research. This is the case in Spain and elsewhere.

In article 2 of the Council of Europe's Convention on Human Rights and Biomedicine the primacy of the human being is established, indicating that "the human being's interest and welfare shall prevail over the exclusive interest of society or science", and in article 21 the prohibition of financial gain is unequivocally introduced: "the human body and its parts shall not, as such, give rise to financial gain." Furthermore, article 22, which refers to the use of parts removed from the human body, envisages that, "when in the course of an intervention any part of a human body has been removed, it may not be stored or used for a purpose other than that for which it was removed, unless this is done in conformity with appropriate information and consent procedures". The Council of Europe has been reiterating the principle of non-commercialization over the years in different declarations. As an example we can cite the Council of Europe's Convention against Trafficking in Human Organs and the Declaration on the prohibition of any form of commercialization of human organs, of 2014. Different international institutions have ordered countries to punish organ trafficking.[32] Additionally, it is important to mention that the European Union's Charter of Fundamental Human Rights also establishes, in article 3, section C, the prohibition of financial gain in the trafficking of the human body and its parts. UNESCO's Universal Declaration on Bioethics and Human Rights indicates in article 21.5, when dealing with transnational practices, that "countries should take appropriate measures, at both national and international level, to combat […] the illicit trafficking of organs, tissues, samples, genetic resources and materials related to genetics".

In the European Union, community legislation closely relates concern over voluntary, non-remunerated donation to the quality of the donations. Directive 2004/23/EC establishes, in article 12.1, that every three years member states must submit reports to the commission on the existing situation in relation to this principle; based on them, the Commission must inform the Parliament and the Council of any additional measures that it considers necessary in relation to the said donations. The report submitted on 21 April 2016 reveals in section 3.4 that, although countries comply with the adoption of measures to ensure voluntary non-remunerated donation, it is difficult to assess their com-

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[32] For example, Resolution 63/22, of 21 May 2010, of the World Health Organization (WHO), which establishes the guiding principles on human cell, tissue and organ transplantation.

pliance exhaustively; it also warns that some practices which are regarded as compensation in one country may represent payment in another, since due to differences in spending power between member states, what is compensation in one country is an incentive in another. The report confirms the difficulties arising from the uneven monitoring and control of registers, and insists that the fact of it being free is a guarantee of safety for protecting human health, since if payment to the donor were allowed they might be tempted to conceal important health data. It is also interesting to highlight the data of the Eurobarometer, according to which only 13% of citizens consider it right to receive compensation for donation.

In the Spanish legal system, the unpaid donation of human organs and tissues is an established ethical principle, and doing business with body parts is considered to be contrary to the dignity of the human being. The legislation supports the general principles of non-remuneration and altruism for donations of organs, cells and biological samples; the specific regulation established for the different fields — for example, egg donation — is based on the same consideration.

What is questionable is that, once this principle has been established, other possibilities are accepted, and principles that seemed solidly established are being watered down in practice and even in the subordinate development regulation itself. Hence the confirmation that once again the legal system operates as a screen to hide the reality, or it at least embellishes it. This also happens in other areas — for example, the theoretical equality between men and women — but, in the case we are looking at here, the gradual and almost imperceptible legitimization that seems to be taking place leads to very profound cultural consequences.

The practical effects of what we are analysing can be seen in the problems posed in practice by subjects such as gestation by substitution; the donation of blood, organs, above all inter vivos; or oocytes; and, lastly, research with human beings, biological samples and healthcare data.

In all these cases the problem arises of the hazy dividing line between legitimate financial compensation, because of the trouble and the expense involved (for example, in the obtainment of eggs), and concealed payment that weakens the wishes of those who agree to donate organs, tissues, and so on. In this respect, gestation by substitution is an extreme case. Although many advocate the individual exercise of freedom by the gestating woman who agrees to this practice, in reality the situation of vulnerability of those who make these decisions in contexts of extreme poverty is not usually taken into account. We shall analyse this issue later on.

6. Rights in genomics

Progress in sequencing people's DNA, and the possibility of activating or silencing genes, or even transferring genes from some species to others, have led to the need for the different treaties and declarations on bioethics to contain specific articles on this subject. Thus, for example, chapter IV of the European Convention on Bioethics is wholly about the human genome and, in the framework of UNESCO, two important documents have been published whose specific object is solely and exclusively the question of genetics: the Universal Declaration on the Human Genome and Human Rights, of 1997, and the International Declaration on Human Genetic Data, of 2003. We shall now analyse some of the principal rights acknowledged in these documents.

6.1. Genes as the heritage of humanity

Article 1 of the Universal Declaration on the Human Genome and Human Rights establishes that:

> The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.

The idea that the human genome belongs to our species as a whole, and not to each individual person, although formulated on a symbolic level, entails very important legal and ethical consequences, among other things because its commercialization, appropriation or even modification concerns us all.

Although the meaning of the first part of the cited article usually goes unnoticed, the idea of linking human identity to the genome presupposes the right to keep it intact for future generations, preserving our uniqueness as a species.[33] In fact, in a context in which it is becoming easier, cheaper and more accessible to modify the genetic makeup of living beings, the obligation not to make alterations that transcend the individual and extend to their descendants has gained legal status. Thus, article 13 of the European Convention on Bioethics establishes that:

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[33] It is understood that our duty is not to modify the human germline in a laboratory. Obviously, our genetic makeup, as occurs with all other living beings, is modified at random and adapted over time.

> An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and *only if its aim is not to introduce a modification in the genome of any descendants*. [The italics are ours.]

In other words, it is licit to use gene editing techniques on the human genome for medical purposes, provided that these interventions do not extend to the individual on whom they are performed and his or her descendants inherit them. The reason is that, if the human germline is modified, this alteration would pass into the genetic heritage of our entire species (the descendants of the modified individual would in turn transmit it to their children, whereby the said modification would be propagated irremediably in our species, with unpredictable effects in the medium term).

6.2. The right for predictive trials to only have a medical or scientific purpose

Can a company require its workers to submit to DNA sequencing techniques to find out how predisposed they are to certain diseases? In reality it is a complex subject, since, for certain professions, it may be useful to know if someone has a predisposition to certain diseases (for example, some type of heart disease that could lead to sudden death). The risks, however, greatly outweigh the potential benefits, given that if the private sector could demand these tests from its workers, they could then be discriminated against because of diseases that, in the majority of cases, belong purely to the realm of hypothesis.

A predisposition to certain diseases does not in fact mean that they will definitely develop, since there are other factors at work: and conversely, the absence of a predisposition is no guarantee that some diseases cannot develop. The information supplied by DNA moves in the context of probabilities, something easy to handle with algorithms but difficult to reconcile later with the actual facts.

Moreover, in the case of diseases that are not only incurable but which cannot be prevented either, there is no personal benefit in knowing that one has a predisposition to them; on the contrary, this knowledge could be devastating from the psychological point of view.

This context of uncertainty is what justifies article 12 of the European Convention on Bioethics:

> Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or a susceptibility to a disease, may be performed only for health purposes or scientific research, and subject to appropriate genetic counselling.

As we see, besides demanding the usual requirements of express consent and medical purposes, the Convention makes it obligatory for the person who has been the subject of sequencing to be counselled by a specialist in order to avoid erroneous, alarmist or media-influenced interpretations.

6.3. The right not to be discriminated against

Article 11 of the European Convention on Bioethics specifies that human beings have the right not to be discriminated against because of their "genetic heritage". Article 7 of the International Declaration on Human Genetic Data states something similar:

> Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing a person's human rights, fundamental freedoms and human dignity.

This type of article attempts to anticipate a scenario that seems to be getting closer and closer, the creation of huge databases with the genetic information of a country's entire population. Even if the purpose of gathering it were, in principle, biomedical, we may suppose that it would be tempting to give the said information other uses, and it would be done sooner or later (for example, selecting workers for a job, looking for a partner or calculating the premium of a private insurance policy).

Moreover, the sequencing of a single individual's DNA also reveals information about their family, and, in certain cases, even about the ethnic group to which they belong. Thus, genetic population studies, very important for scientific knowledge, may easily give rise to spurious conclusions applicable to a human group.

For this reason, article 7 of the International Declaration on Human Genetic Data, under the heading "Non-discrimination and non-stigmatization", establishes that:

> a) Every effort should be made to ensure that human genetic data and human proteomic data do not […] lead to the stigmatization of an individual, a family, a group or communities.
> b) In this respect, the appropriate attention should be paid to the findings of population-based genetic studies and behavioural genetic studies and their interpretations.

This idea was included, for example, in article 58.6 of the Spanish Law of Biomedical Research, Law 14/2007:

> 6. In studies on genetic diversity, local and ethnic traditions will always be respected, at all times avoiding practices of stigmatization and discrimination.

Lastly, the recent important regulation adopted by the European Union to protect personal data has explicitly stated the risks of bio-computing and big data.

> Personal data which are, by their nature, particularly sensitive in relation to fundamental rights and freedoms merit special protection, as the context of their processing could create significant risks for fundamental rights and freedoms. Such personal data should include those revealing racial or ethnic origin, whereby the use of the term "racial origin" in this Regulation does not imply an acceptance by the Union of theories which attempt to determine the existence of separate human races.[34]

The objective of these precautions is to prevent the massive treatment of genetic data making it possible to draw racist, xenophobic, stigmatizing conclusions. The risk, always present in this kind of collective study, is that past or contemporary inequalities are justified by virtue of supposed moral or behavioural qualities conditioned in an irremediably deterministic way by human genes. The statistical correlations that are sometimes established in different pseudoscientific studies, for example, between gene mutations and poverty, or between financial success and genetic seniority of the reference population, cause incalculable harm to certain groups and discredit social and egalitarian policies.

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[34] Regulation (EU) 2016/679, of the European Parliament and the Council, of 27 April 2016, relative to the protection of natural persons with regard to the processing of personal data and the free circulation of these data. Considering 51.

6.4. The prohibition of making financial gain from genetic heritage

Can human beings' genes be patented? The general rule is that the genetic makeup of our species belongs to humanity as a whole, whereby it cannot be the object of individual or commercial appropriation.

The same thing happens with the genes of all other living species, especially those that have coexisted symbiotically with certain indigenous communities since time immemorial. In fact, article 26.2 of the Cartagena Protocol on Biosafety of the Convention on Biological Diversity (Montreal, 2000), after citing "the value that biological diversity has for indigenous and local communities", establishes the following:

> 2. The Parties are encouraged to cooperate in the sphere of information exchange and research into the socioeconomic effects of modified living beings, especially in indigenous and local communities.

The issue, however, is not that simple. Until the 1980s there was consensus that living beings could not be the object of a patent. The pressure of the powerful biotechnological, pharmaceutical and biomedical industry soon reverted this axiom. The first to be allowed was the patent for bacteria (Diamond v. Chakrabarty, SC, USA, 1980),[35] followed by mammals (Harvard mouse), then human organs (Moore)[36] and finally, genes (Myriad).[37] Although there are many nuances that we cannot explain in this chapter, it may be said that it is currently possible to patent not just genes, including those of our species, but any living being, along with its offspring, with the sole exception, we imagine for now, of human beings.[38]

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[35] In Diamond v. Charkrabarty, the American Supreme Court agreed, by five votes to four, to grant a patent on a bacterium that, genetically modified, degraded crude oil.

[36] John Moore was an American citizen who suffered a particular kind of leukaemia. They removed his spleen and saved his life. The doctors created a cell line from the T-lymphocytes of the spleen they had removed and patented it in 1984, all of this without telling the patient anything. When Moore went to court alleging that the spleen was his property and that he at least had a right to share in the profits generated by this patent, the courts found that the removed organ was discarded material and he had no right to it at all.

[37] A company discovered the relationship between some mutations in certain genes and breast cancer. When patenting its discovery, women had to pay large sums of money to gain access to a diagnostic trial and they also could not get a second opinion. The American Supreme Court eventually ruled against the company, but it held this monopoly for years.

[38] López Baroni, M. J. (2018). "El criterio de demarcación en las Biopatentes." *Anales de la Cátedra Francisco Suárez,* 52, pp. 131-153. See also by Casado, M. the chapter "Patentes...", in Mayor Zaragoza, F. and Alonso Bedate, C. (coords.) (2003). *Gen-ética.* Ariel.

In fact, the wording of article 4 of the Universal Declaration of the Human Genome and Human Rights is ambiguous: "the human genome *in its natural state* shall not give rise to financial gains" [our italics]. This wording indirectly legitimates patents for human genes when a "non-natural" intervention has been performed. And this is the interpretation made by the Directive on biotechnological inventions[39] and the European Court of Justice, when deciding if this law was in keeping with the values that shape the EU.[40]

7. Recommended reading

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[39] Directive 98/44/EC of the European Parliament and the Council, of 6 July 1998, relative to the legal protection of biotechnological inventions. LCEur 1998\2471.

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4

Sexual and Reproductive Health and Voluntary Termination of Pregnancy

1. INTRODUCTION[1]

Attitudes to abortion are almost inevitably split in a remarkably visceral confrontation between supporters and detractors, who rather than constructing possible paths to agreement seem determined to discredit the other side and turn the debate into a clash of absolutes. In our opinion several facts and arguments must be taken into consideration for a correct bioethical analysis.

Firstly, any discussion of abortion implicitly carries with it two different aspects that ought to be separated: on one hand, the right to lead a healthy sex life — freely decided, of course, within the options and contexts that each person chooses — and on the other, the right to have children and to plan one's family. Therefore, the first thing to do is to think about good sexual and reproductive health (which, as a consequence, would notably reduce unwanted pregnancies).

It is obvious that sex and reproduction are involved and intertwined and that, moreover, they conceal underlying individual and social fears and taboos, inculcated for centuries. It must not be forgotten that the control of sexuality has been a form of power, exercised by churches and patriarchs, not only over women — although this is the key element — but over men too. Fear of "the consequences", both reproductive and those referring to the transmission of diseases, or moral condemnation, have anathematized generations, but this has obviously never stopped people doing it.

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[1] Most of the arguments discussed below are included in the *Document on Involuntary Termination of Pregnancy,* http://hdl.handle.net/2445/11453; the *Document on Sexual and Reproductive Health in Adolescence,* http://hdl.handle.net/2445/11370; and the *Document on Conscientious Objection in Health Care* http://hdl.handle.net/2445/11376. The regulatory impact of these texts in current relevant Spanish legislation is included in *New edition and analysis of the regulatory impact of the Bioethics and Law Observatory's documents on sexual and reproductive health in adolescence and on voluntary termination of pregnancy*, http://hdl. handle.net/2445/104592.

Sexuality constitutes an element of pleasure, wellbeing and balance that is essential in people's lives, and it is therefore necessary for information, attention and advice about it, in all its forms, and about methods of contraception, to be available to all and truly accessible. The effective and efficient separation of sex from reproduction is a very recent occurrence, as only in the early 1960s, with the contraceptive pill, was this dissociation safely achieved. This was one of the greatest revolutions of the century — comparable in its scope to women being given the vote, for example — although it must be admitted that its repercussions are very different in industrialized countries and less developed ones, where there has been no widespread adoption of its use, since ensuring easy access to the different contraceptive methods is little short of impossible in a context of poverty.

2. Consequentialist arguments

Abortion has been prohibited and practised in every society for centuries, but its prohibition has merely led to it being performed in secret. This has made the circumstances of discrimination between men and women worse, and among women too; between those who, with better financial, social and cultural circumstances, have been able to have a safe abortion — even travelling to another country with different laws and healthcare practices — and those who have not.

In our opinion, abortion is a problem of public health and legal policy, not just a matter of conscience; the existence of proper regulation to delimit the legal cases and provide guarantees for its practice is an unavoidable matter of legislative policy for countries. Having an abortion or not, in each particular case, is a moral question, of individual awareness, that everyone has to resolve. All abortion laws must be accompanied by good sexual and reproductive health policy to facilitate access to information and contraceptive methods, and to encourage responsibility in one's sex life, so that abortion is not the first option; such policies must be part of public policy in a plural, social state under the rule of law. Nevertheless, in Spain the reality shows us that there is no place for sex education in school curriculums, but it is taught according to the goodwill and the possibilities of parents and teachers in each school.

It is a fact — although some sectors do not even want to accept it — that lessons on the subject of sex and reproduction would notably reduce the number of cases in which women are forced to make tragic and painful decisions. Naturally, not all cases would be resolved, but it is a fact that the number of abortions would be reduced, as would the confrontation between attitudes that lead to clashes of absolutes between "warring factions" — they can only be described as such, as it seems to be a fight between different sides who do not even agree on the concept of dignity or human rights. Good quality sex education, not attaching blame, but based on responsibility, helps people to take control of their own behaviour, take the relevant steps to reduce risks, and avoid unwanted effects. In other words, sex education and access to contraceptive methods bring about a considerable reduction in the number of abortions: all those that are performed because of a lack of information and access. In this way the voluntary termination of pregnancy would be a solution in cases where the measures have not been sufficient and, specifically, it would resolve the instances in which the woman's life and health are at stake, or where malformations of the foetus have been detected, or serious unforeseen circumstances have arisen that make it necessary to resort to it.

The decision to terminate a pregnancy entails having to choose between various "evils" and options that may be placed in order differently, but which always represent a fateful decision for the woman, who is the one who has to decide, and also for those who intervene in the act. Therefore, with respect to abortion, a fundamental question is — as Resolution 1607/2008 of the Council of Europe[2] points out — to clearly show that abortion is the unwanted outcome of a previous problem: unwanted pregnancy. Not wanted because it was the result of a forced sexual relationship, because it endangers her health, because the foetus presents malformations, because it changes her life, or, quite simply, because it was not planned. In the majority of cases, abortion is the consequence of very poor or non-existent sexual and reproductive education and of inadequate access to the birth control methods that women have to use and, as has been said, it has particular repercussions on those who are in a very underprivileged social and financial situation.

In any case, it would be appropriate to delimit the controversy over the regulation of abortion. Very often the issue ought not to be focused yet again on discussing the morality of abortion, as laws on the voluntary termination of pregnancy already exist in more than two-thirds of the countries in the

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[2] Resolution 1607/2008, of 16 April, of the Assembly of the Council of Europe, which urges member countries to legalize abortion, establishing reasonable time limits for it, and to guarantee the effective exercise of women's right to an abortion free of medical or legal risks, respecting women's right to choose and offering them conditions for a free and informed choice. It also urges its members to eliminate real and regulatory restrictions on gaining access to risk-free voluntary termination of pregnancy, creating the appropriate healthcare conditions and providing suitable funding. Available at: http://assembly.coe.int/main. asp?Link=/documents/adoptedtext/ta08/fres1607.htm.

world,[3] and moreover abortion has never been equated with murder in sentences, grief or public sentiment.[4] In our opinion, reasons in favour of or against the type of regulation or modification proposed need to be put forward.

In comparative law, abortion can be regulated by a law that includes indications of de facto instances where behaviour is decriminalized; by a law that sets legal time limits for abortion; and through a mixed system in which the system of time limits is observed during the first weeks of gestation, after which indications and prohibition come into play. Most countries adhere to the system of indications, and the performance of abortions is decriminalized (done with the consent of the pregnant woman and meeting certain requirements) in different instances, of which the most commonly accepted are: danger to the mother's life or health, when pregnancy is a consequence of — previously reported — rape, malformations of the foetus, and so-called social or socioeconomic indication. Different evaluations of the conflict between the real rights of the woman and the potential rights of the embryo or foetus — which the Spanish Constitutional Court does not consider a person but a "legally protected asset"[5] — underpin the adoption of one or another technique.

3. The value of the life of the foetus and women's rights

The moral status of the foetus is the subject of heated discussion, and about which it seems impossible to reach peaceful agreement.[6] While there is a high degree of consensus with regard to the biological facts and criteria of gradual-

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[3] It is interesting to visit the webpage worldabortionlaws.com/map, as one can observe the situation of abortion all over the world and note the correlation between the north and south, between countries where abortion is prohibited and poverty.

[4] "Throughout our entire legal history the life of the foetus has been protected to a lesser extent than independent human life. Therefore, among other things, the punishment is, and has always been, far lighter in abortion than in homicide. For the law, the confirmation of the existence of a person with rights and responsibilities is diverse from the moment when a life cycle begins that will give rise to a person. In other words: *the prenatal process does not confer the status of person*; this condition is only acquired with birth (art. 29 CC) and therefore it is subject to the fundamental right to life envisaged in article 15 CE and article 2 CEDH." *Ruling on the scope and limits of the therapeutic and eugenic indications of voluntary termination of pregnancy*, requested by the Department of Health of the Generalitat de Catalunya, issued by Mirentxu Corcoy Bidasolo, Santiago Mir Puig and Joan Josep Queralt Jiménez, professors of Criminal Law, University of Barcelona.

[5] See the sentences of the Constitutional Court 53/85, 212/86 and 116/99.

[6] On the need to find a solution, see Singer, P. (1997). *Repensar la vida y la muerte. El derrumbe de nuestra ética tradicional*. Barcelona: Paidós.

ism are accepted, from the legal point of view as well, since birth is considered to be the moment when a person acquires rights, the same is not the case for termination of pregnancy.

From a philosophical point of view attempts have been made to find a criterion indicating which beings have full moral rights; the problem is that the criteria given are not universally accepted and they may also clash with one another, or lead to absurd or contradictory consequences in their application. Sensitivity, the capacity to feel suffering and pleasure; consciousness, the capacity to be aware of itself and its surroundings; the capacity to anticipate and relate to others; the capacity to have a moral conscience, to distinguish between good and evil … and so many others that, nevertheless, applied to foetuses lead us to the paradox that it is in practice impossible to grant foetuses equal rights without cancelling out those of women.

It is therefore necessary to introduce to the debate two interesting elements: *a*) the distinction made about potentiality. Foetuses are potential people but they are not fully developed yet (just as although all oak trees have been acorns, not all acorns become oak trees, according to the well-known aphorism); *b*) the idea that supra-conformist forms of behaviour — the "good Samaritan" — are not required (and even less so in criminal law); hence it should not be considered a woman's obligation to continue with an unwanted pregnancy that may imply taking risks she does not want to.[7]

Between the clash of absolutes that arises when the foetus is granted predominant rights over those of the woman, prohibiting abortion under any circumstances, or giving the woman absolute rights to decide freely about her own body, at any time, the proposed position is gradualist and very reasonable.[8] At the beginning of pregnancy, it is understood that the woman's decision over the potentiality of a life at the embryonic stage takes precedence, and,[9] establishing time limits, the decision is left in the hands of the subject with rights (the woman), respecting her autonomy without the need for controls by

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[7] See Warren, M. (1995). "El aborto", in Singer, P. (coord.). *Compendio de ética.* Madrid: Alianza Editorial. Also very interesting is the controversy between Thomson and Finnis, the Spanish version of which is included in *Debate sobre el aborto. Cinco ensayos de filosofía moral. Madrid:* Cátedra, colección Teorema, 1992.

[8] The idea of the three trimesters associated with viability comes largely from the famous case Roe V. Wade, in 1973. See also Dworkin, R. (1994). *El dominio de la vida. Una discusión acerca del aborto, la eutanasia y la libertad individual.* Barcelona: Ariel, where an idea of the sacred nature of non-religious, secular life is defended, hugely interesting.

[9] See Mitjans, E. (2007). "Bioética e igualdad en la interrupción voluntaria del embarazo." In: Casado, M. (coord.). *Nuevos materiales de bioética y derecho.* Mexico City: Fontamara, pp. 209-228.

third parties, doctors or psychologists. From thereon it is considered that as the foetus acquires greater viability, greater measures of protection are required; therefore, only the indications of serious danger for the life and health of the mother and malformations of the foetus are maintained.

The most basic and intuitive idea of rights leads the possibility of making one's own decisions about life options back to terms such as freedom, dignity and justice. "The right to decide" is the cry of the Enlightenment, of "dare to know and to decide", which today still arouses so much fear and reticence, and which is so often claimed to be contrary to communal co-existence, ignoring that deciding freely does not mean harming coexistence, but that it needs to be made compatible with the freedoms of others.

4. REGULATION IN SPAIN

4.1. Regulation before the enactment of the Law of Legal Time Limits

In Spain, before the current Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy, of 2 March 2010, was passed, which will be analysed in the next section, legislation already existed that allowed abortions to be performed in certain cases (which will also be analysed later),[10] and yet the need to change the law and the way in which the pre-existing law had been applied had been extensively and repeatedly questioned. The previous law was in force in the long period from 1985 to 2010 and not even the total reform of the Criminal Code — in 1995 — modified it. Passed at the end of the political transition, after the period of the Franco regime it seemed the only one possible at the time. Through its long period in force, it proved to be so necessary that successive governments — despite their overall majorities — neither suppressed it nor restricted it, nor even tried to limit the extensive interpretation with which it was being applied. And it is well known that the scope attributed in practice to the third instance of the current law went much further than what its own formulation indicated, since through the gradual extension of the concept of mental health, it in fact introduced the social indication.

Although it covered obvious social needs and problems fully deserving of support, this generated a situation of legal uncertainty repeatedly pointed out

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[10] Organic Law 9/1985, of 5 July, of The Decriminalization of Abortion in Certain Cases.

by jurists and the different groups involved. The changes in criminal law policy are effectively possible and the attorney general could have ordered each of the "legally" practised cases of abortion to be thoroughly investigated. In this respect, it should also be remembered that many healthcare workers are still unaware of the real possibilities of the legal framework and they find it safer to pretend not to know about the problem or to refuse to collaborate in acts that have legal consequences unknown to them.

Thus, in this context, it may be said that the reform of the abortion law with the aim of its conditions being clear and accessible had become a democratic demand to give women legal certainty, while at the same time respecting those who have an abortion and those who do not.

Along with all these facts and precedents, let us remember that women's reproductive autonomy has been an internationally acknowledged right ever since the International Conference on Population and Development in Cairo in 1994 went further than the generally accepted association with the concepts of family planning and contraception, and defined sexual and reproductive health as the possibility of having a responsible, satisfactory and safe sex life, and it understood reproductive rights as the capacity to freely determine whether one has children or not.

At this point we ought to add that the University of Barcelona's Bioethics and Law Observatory has been drafting various documents on the subject with considerable repercussions in the media and public opinion. The science associations involved have echoed its recommendations, and they have even had a big impact on the law, since the various regulations — at state and autonomous community level — include many of its proposals. There is the *Document on the Voluntary Termination of Pregnancy*, in which we make a proposal to change the law in Spain and in which we include additional measures that we had published previously, in the *Declaration on Sexual and Reproductive Health in Adolescence* and the *Document on Conscientious Objection in Healthcare*. These publications, along with other similar initiatives, have had an impact on the debate in society and have generated ideas for the creation and / or updating of healthcare institutions' protocols of action referring to this subject. These initiatives include the *Report on the Termination of Gestation* drafted in 2008 by the Bioethics Advisory Committee of Catalonia.[11]

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[11] It can be consulted at www.gencat.cat/salut/depsalut/html/es/dir89/intgestesp.pdf.

4.2. The Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy

4.2.1. The history of the drafting of the law

The result of the precedents mentioned so far was that — at the request of the Ministry of Equality, something in itself open to interesting interpretations — on 14 May 2009 the Council of Ministers passed the draft bill of the Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy.[12]

After that a series of rulings and reports on the draft bill were issued, some due to statutory requirement and others — like the one by the recently created Spanish Bioethics Committee — at its own request.[13] Of them it is interesting to mention the Report of the Prosecution Advisory Board, of June 2009, and the Ruling of the Council of State, of September that same year.

On 26 September the Council of Ministers passed the bill, which was published in the Official Bulletin of Parliament on 2 October 2009. After the corresponding parliamentary channels in Congress and the Senate, the new Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy was finally passed on 2 March 2010, and came into effect on 4 July of that year.

In the period from the draft bill to the text eventually passed modifications were introduced that, in our opinion, have left the articles of the legal text looking more and more like a programme rather than a specific regulation. Many of its articles are a declaration of good intentions, so the interpretation being given to the precepts — in too many cases, very open — will determine its application, and only with the passage of time will we see if the new law has provided the longed-for legal certainty that was so badly lacking with the previous law. Or if it does indeed represent progress for women's rights, as is claimed in the Preamble, postulating that "The first duty of the legislator is to adapt the law to the values of the society whose relations it has to regulate, always ensuring that new legal regulations generate certainty and security in

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[12] It could be said with satisfaction that the draft bill included many of the conclusions and proposals of the aforementioned Documents of the Bioethics and Law Observatory and that it had, moreover, an interesting and enlightening exposition of reasons.

[13] Spanish Bioethics Committee, Opinion on the bill for the Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy, 2009. Available for consultation at www.comitedebioetica.es/documentacion/docs/consenso_interrupcion_pregnancy_comite_bioetica_oct_2009.pdf.

those to whom they are addressed, as freedom only finds refuge on the firm ground of the clarity and precision of the law".

At the same time, this Preamble makes it clear that "The law comprehensively tackles the protection and guaranteeing of rights relative to sexual and reproductive health. It introduces the definitions of the World Health Organization in reference to health, sexual health and reproductive health in our legal system and provides for the adoption of a series of actions and measures in both healthcare and education". It is also important to mention that, based on national and international law, on the sentences of the Spanish Constitutional Court and those of the European Court of Human Rights, "This law recognizes the right to freely decided maternity, which among other things implies that women can make the initial decision about their pregnancy and that this decision, conscious and responsible, must be respected". The decision adopted of establishing a mixed system "of time limits" in the first 14 weeks of gestation combined with a later one of indications is justified in this way.

4.2.2. General requirements

The general requirements for terminating pregnancy are (Art. 13):

1) That termination of pregnancy be performed by a specialist doctor or be carried out under his/her supervision.
2) That it be carried out in a public or private healthcare centre that has been previously authorized.
3) That it be carried out with the express consent in writing of the pregnant woman, or, where appropriate, of her legal representative, in accordance with the stipulations of Law 41/2002, Basic Regulator of Patient Autonomy and of Rights and Responsibilities in matters of Information and Clinical Documentation. Express consent may be waived in the case envisaged in article 9.2b) of the said law.

The question of consent through representation is especially important in the case of abortion, as the case law that may be present (minors up to the age of 15; minors aged 16 and 17; and persons with disability, who may have very different levels of autonomy) generates quite a few problems.

The law of Patient Autonomy, to which the Law of Voluntary Termination of Pregnancy refers, stipulates the following (Art. 9):

3. Consent through representation will be granted in the following cases:

    a) When the patient is incapable of making decisions, in the opinion of the doctor in charge of their care, or their physical or mental state does not allow them to be aware of their situation. If the patient has no legal representative, consent will be given by people related to them for family or de facto reasons.
    b) When the patient's capacity has been legally modified and this is stated in the sentence.
    c) When the patient is a minor, incapable either intellectually or emotionally of comprehending the scope of the intervention. In this case, consent will be given by the minor's legal representative, after listening to their opinion, in accordance with the provisions of article 9 of Organic Law 1/1996, of 15 January, of Legal Protection of Minors.

We can thus distinguish four classes of autonomy in reference to the termination of pregnancy:

a) Women aged 18 and over. They have full autonomy.
b) Minors aged 16 and 17. The original wording of the law (2010) allowed them to have an abortion not only without their parents' consent (it was enough for one of them to be informed), but also, if there was a conflict of interests, without their knowledge. Nevertheless, in 2015 the Partido Popular reworded this part and, for a girl of that age to be able to have an abortion, the express consent of her parents was obligatory and necessary (we shall analyse in detail the ideological context of this reform in a later section), as well as that of the minor.
c) Minors aged 15 and under. Besides the specific consent of their parents, the minors' consent will be necessary. In the event of their age or circumstances not permitting it, it will be enough to know their opinion, which must be taken into account.
d) Persons with some degree of disability, who in turn may or may not be minors, and who may also be totally or partially legally incapacitated, or even not be. Given that there is a huge body of case law in these cases, each specific case will have to be considered in order to assess whether their consent, their opinion, and possibly the consent of their parents or guardians is necessary.

4.2.3. System of time limits

The main new aspect of the law is that it makes it possible to terminate pregnancy without having to justify the reason (Art. 14). The only substantial requirement is that termination must take place within the first 14 weeks of gestation.

As to the formal requirements, apart from the woman's consent, it will be necessary for her to be informed of her rights, services and help in the event that she decides to continue with the pregnancy, and there must be a three-day gap between the moment she is offered this information and when the abortion is performed.

This is the most noteworthy aspect of the law, as it means it is the woman who decides freely and voluntarily to continue or not with the pregnancy, without having to justify, explain or argue, in the event of termination, why she does not wish to continue with it.

Causal (justified) abortion is limited to the cases of danger to the mother's health or anomalies in the foetus. Abortion because of rape, which in the previous Spanish law had to be reported, and the abortion had to be performed within the first 12 weeks, disappears. It has been absorbed by a generic system of time limits without specific causes.

4.2.4. Termination for medical reasons

Besides the previous case, the law envisages termination of pregnancy for medical reasons provided the following requirements are met:

4.2.4.1. Risk for the pregnant woman's life or health

This is what is known as therapeutic abortion. The only requirement is that it be performed up to and including week 22 of pregnancy. A medical ruling must be issued prior to termination of pregnancy, unless the woman's life is in danger, in which case it can be omitted (Art. 15).

Moreover, in the event of risk for the woman's life or health after week 22 of pregnancy, what is required is not an abortion but an induced birth. As the law says, "the woman's right to life and physical integrity and the interest in protecting a life in the process of development are fully harmonized". It is important to stress that this rule does not appear in the articles of the law, but in the preamble, something that is anomalous from a technical point of view, as it may generate legal uncertainty in such an important matter.

In the previous Spanish law these two cases were not distinguished, as they are now, as there was no limit whatsoever to performing an abortion in the case of risk for the physical or mental health of the mother, and nor was induced birth envisaged, expressly at least.

4.2.4.2. Serious anomalies in the foetus

This is what is known as eugenic abortion. The only requirement is that it should be performed within the first 22 weeks of gestation and the serious anomalies of the foetus are stated in a ruling issued prior to the intervention by two specialist doctors other than the one who is performing or supervising the abortion.

4.2.4.3. Foetal anomalies incompatible with life or an extremely serious and incurable illness of the foetus

The law distinguishes between the serious anomalies of the foetus, which allow for the termination of pregnancy within 22 weeks as described above, and the anomalies incompatible with life or an extremely serious and incurable illness of the foetus, in which case there is no limit to terminating pregnancy. The law does not specify what the differences between the two categories are.

The only formal requirement is that foetal anomalies must be stated in a medical ruling by a specialist other than the one performing the intervention, and, in the case of serious and incurable illness, that this be confirmed by a clinical committee.

In the previous Spanish legislation this distinction did not exist, so eugenic abortion came under a single expression, “serious physical or mental defects”, and the abortion was required to be performed during the first 22 weeks.

4.2.5. Regulation in criminal law

We ought to point out that the existence of a law of legal time limits for termination of pregnancy has not led to the criminal law on this subject being repealed. The Criminal Code continues to punish abortion, although with lighter sentences than in the previous system, adapted, logically, to the new regulation.

The woman who has an abortion (the Criminal Code uses the term "abortion", while the new law uses the expression "termination of pregnancy") will be punished with a fine lasting six to 24 months (each day or month of the fine is equivalent to a particular sum of money according to the guilty party's personal characteristics).

Those who perform the woman's abortion, with her consent, will be sentenced to one to three years in prison and be disqualified from working in the medical profession for a period of between one and six years (Art. 145). In Spain, if the prison sentence is less than two years and the person has no criminal record, it is usually suspended, and they will not have to go to jail.

If one observes the regulation, it can be seen how even in cases in which the abortion law is broken, neither the woman nor the healthcare personnel will go to prison: the former, because she will have to pay a fine, and the latter, because if there are no aggravating circumstances they will be sentenced to less than two years, whereby in principle they would not go to jail (there is an aggravated subtype by which, if the abortion were performed after 22 weeks, the judge would impose the higher scope of the sentence. In the case of the woman the fine would be higher, but in the case of the healthcare personnel the sentence would be between two and three years in prison, which would increase the likelihood of having to go to jail).

If the abortion were performed in accordance with the substantial requirements established in the law (risk for the mother, unviability of the foetus or abortion for no reason but within the first 14 weeks), but without satisfying the formal requirements (information for the mother, not observing the three-day period, clinics' lack of authorization, the absence of rulings, and so on), the Criminal Code exempts the woman from punishment but penalizes the healthcare personnel with a fine and disqualification.

4.2.6. An attempt to reverse the reform[14]

In order to understand the attempted repeal that this law has undergone with the new government (the law was passed in 2010 by a socialist government and in 2011 a conservative government won the election), we have to place this

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[14] In this debate the article by M. Casado is interesting: "Consecuencias para las mujeres y su salud de la posible reforma de la ley del aborto." Gac Sanit., 2014; 28 (6): 498-500. Also, in the editorial of *Gaceta Sanitaria*, vol. 26, no. 3, May-June 2012, pp. 201-202, see "¿Es la maternidad lo que hace auténticamente mujeres a las mujeres?", by M. Casado.

law's process of gestation in its historical context, and so we must take a brief look back at how abortion has been regulated in Spain:

1) The Criminal Code of 1973, passed during the Franco dictatorship (the dictator died in 1975), was the one used, with some modifications, in the democratic period in Spain until 1995. In other words, from 1978, when the Spanish Constitution was passed, to 1995 the Criminal Code of the dictatorship continued to be used. This Code punished abortion with jail sentences of between six months and six years, for both the woman and the healthcare personnel. If the mother had the abortion to "hide her dishonour" (getting pregnant out of wedlock), then the sentence could be six months in jail at the most, which symbolized the clerical and paternalistic spirit of the period. Furthermore, the sale or distribution of contraceptives was also banned (up to six months in jail).

2) This Criminal Code of 1973 was reformed in 1985 by the PSOE with the aim of decriminalizing abortion in three cases: rape, risk for the mother and anomalies in the foetus. The other penalties remained the same between 1985 and 1995 (when the new Criminal Code was passed). That is, that if an abortion was performed outside the three cases allowed, the punishments continued to be very high, up to six years in jail. What the socialist government did in these cases was to pardon the women after they had been sentenced in court.

3) In 1995 the democratic Criminal Code was introduced, almost 20 years after democracy was a fact in Spain, also under the socialists. This code left the situation of abortion virtually intact. That is, it was still decriminalized in the three cases mentioned, but the sentences for the cases in which it was performed outside these three cases were reduced: a fine or six months to a year in prison for the woman (one-year prison sentences could also be substituted by a fine, whereby the legislator made sure that the woman did not go to prison), and a spell in prison of between one to three years and disqualification for the healthcare personnel (just like now).

4) In 2010, 15 years after the democratic Criminal Code was passed, and more than 30 years after democracy returned to Spain, the Law of Voluntary Termination of Pregnancy that we have been analysing was passed.

The most conservative sectors of the Partido Popular and the government of the Autonomous Community of Navarre, also conservative, appealed against this law in the Constitutional Court.

When they lodged the appeal, the court was asked to suspend the application of the law until the appeal was heard, which would have halted the application of the law for many years. Nevertheless, the Constitutional Court ruled out taking that precautionary measure, and this is why the law is still in force now despite the fact that, eight years later, we are still waiting for a sentence to be issued.

In 2011, the socialist government of José Luis Rodríguez Zapatero, which brought in the law, called an early general election due to the economic crisis. Mariano Rajoy, the leader of the Christian democratic Partido Popular, included in his manifesto the idea of repealing the Law of Voluntary Termination of Pregnancy as soon as he won the election.

The Partido Popular won and obtained an overall majority, which implied that it could modify the Law of Voluntary Termination of Pregnancy without the support, or even with the opposition, of the rest of the political parties. The principal architect of the counter-reform was the Minister of the Interior, Alberto Ruiz Gallardón, spurred on by the most conservative sectors of Spanish society. His project was entitled the "draft bill of the organic law for the protection of the life of the unborn child and the rights of the pregnant woman". The title could not be more significant, since the proposal revolved around the embryo and pushed the woman into the background. To everyone's astonishment, not only did the content of the counter-reform not return to the three legitimate cases for abortion of 1985 (rape, risk for the mother and malformation of the foetus) but it was even more restrictive, forcing the woman to continue with the pregnancy even in cases of malformation of the foetus. It is worth taking a close look at the attempted reform to understand the full scope of its perverse nature:

a) It punished "incitement" to abortion outside the three cases permitted by the law, with prison sentences of one to three years. With the reform, the woman was not punished, whether she caused the abortion voluntarily or through lack of caution. According to the doctrine (Muñoz Cuesta, 2014),[15] the instigator was sanctioned to prevent the incitement from going unpunished applying the general rules (if the woman cannot commit a crime of abortion, then the instigator could not be punished for incitement to a "non-crime", hence he or she should be punished specifically). The pun-

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[15] Muñoz Cuesta, F. "Algunas consideraciones sobre el Anteproyecto de Ley Orgánica de modificación del delito de aborto." *Revista Aranzadi Doctrinal*, no. 10/2014, BIB 2014/46.

ishment of incitement with such a high sentence would have been a sword of Damocles for the people close to the person who wished to have an abortion.

b) For a woman to be able to have an abortion for "psychological reasons",[16] these had to cause "serious, permanent or long-lasting damage to her health", a requirement that generated a fair amount of uncertainty (how to calculate permanence? How long did the damage have to last?). The Attorney General's Office warned that this requirement would increase the number of accusations due to abortion, since the 1985 reform did not distinguish between damage that was "permanent in time" and "non-permanent".

c) If the foetus might be born with malformations or with serious physical or mental defects, the woman could not have an abortion, according to the Regulatory Impact Analysis Memorandum, because "the law cannot condition the value of the life of the unborn child to the expectations of its possible future disability, whereby it is excluded from the article, as an indication for the decriminalization of abortion".

The reform only permitted abortion if the foetus presented "an anomaly incompatible with life",[17] which, in its own words, was "associated with the death of the foetus or the newborn baby during the neonatal period".

Even so, it was not enough for the foetus to be about to die, the mother in this specific case (death, not an anomaly or illness in the foetus) was further required to show that it was causing "serious danger to her mental health", which also "had to be permanent" (that is, the damage to her mental health had to last after the death of the foetus, for an unspecified but presumably much longer time.[18] The woman therefore had to perform

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[16] The wording read, "That it be necessary, as the conflict cannot be resolved, from the field of medicine, in any other way, to avoid serious danger for the life or the physical or mental health of the pregnant woman, provided that it is performed within the first 22 weeks of gestation. For these purposes, it will be understood that there is serious danger for the life or the health of the woman when pregnancy produces important damage to her health, permanent or long-lasting, according to medical scientific knowledge at that time, and it is thus stated in a report motivated and issued previously by two doctors in the speciality corresponding to the disease that generates the serious danger for the woman, different from the doctor who performs the abortion or under whose direction it takes place, and who do not work in the centre or establishment in which it is performed". Draft bill for the Organic Law for the protection of the life of the unborn child and of the rights of the pregnant woman.

[17] This situation normally refers to cases of anencephaly.

[18] The literal tenor is as follows: "In the event that the serious danger for the mental health of the woman originates in the existence in the foetus of some anomaly incompatible with life, the report required in the previous paragraph will be issued by a single doctor [...] Abortion will not be punish-

a veritable legal and medical balancing act, through medical rulings, to be able to have an abortion in the sole event of certain death of the foetus after it had been born.

d) The possibility was brought back of having an abortion in the case of a crime against sexual freedom, but it was hugely restricted for minors. Thus, in the case of girls of 16 and 17 who were not emancipated, their parents had to give their "consent" (a euphemistic expression that means that if the parents did not want their sexually assaulted daughter to have an abortion, she could not do so legally). If the minor was under 16, the law required the parents' consent for her to be able to have an abortion. In the case of disagreements between the parents and the minor, a judge would decide, with uncertain criteria. Thus, let us imagine that a 17-year-old girl became pregnant after being raped. The parents and the judge could force her to have the baby, since the judge was legally entitled to refuse her the right to have an abortion if he/she considered that the girl "was not mature enough" to give consent. All this with the inherent contradiction in a law code that presupposed that a girl of 14 was mature enough to get married, but not to have an abortion three years later as a result of sexual assault.[19]

   Lastly, if the minor was under 16, the judge had to take into account, above all, the opinion of her parents (who, a priori at least, would be against abortion, otherwise they would obviously not have gone to court; although an even more paradoxical situation could arise: that the minor does not want to have an abortion, but her parents do want her to, and a judge has to decide).

e) Moreover, even in just the two cases in which abortion was accepted (risk for the mother and sexual assault), the woman had to previously undergo indoctrination therapy in which she would be informed of the risks of abortion "for the woman's health and for her future motherhood" and of the "expectations for the development of the child's life". There was even the possibility of other professionals and even relatives participating (if she could not be convinced, one supposes). If the woman managed to survive to this stage,

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able, even if 22 weeks of gestation are exceeded, provided that the anomaly incompatible with the life of the foetus had not been previously detected or it had been impossible to detect, with an accurate diagnosis, and it is thus stated in the report issued previously, in accordance with that required in this section, or when there is a risk for the woman's life that is unavoidable, within what is clinically exigible, through the protection of the life of the conceived baby through induction to childbirth." Draft bill for the Organic Law for the protection of the life of the unborn child and of the rights of the pregnant woman.

[19] The minimum age for marriage was raised to 16 in 2015.

then she could have an abortion, but she had to let a minimum of seven days pass. Moreover, the doctor who had taken part in the information had to issue a certificate without which the clinic could not perform the abortion (the law did not envisage what would happen if the doctor refused to issue the certificate, or if he or she became ill).

f) It extended the conscientious objection of healthcare personnel to cover virtually any act or member of staff involved, as they could "refrain from any participation or collaboration in the voluntary termination of pregnancy".

The reform was favourably reported on by the Spanish judges' governing body, the same General Council of the Judiciary that could not reach agreement to report on the Law of Time Limits in 2010.[20] Even worse, for its inconsistency, was the attitude of the Spanish Bioethics Committee. In 2009 this body reported favourably on the Zapatero government's Law of Time Limits by 11 votes to one. And in 2014, it was in favour of Gallardón's reform by the same margin. How can such nonsense be explained? Well, when the Partido Popular came to power in 2011 it replaced the members of the Spanish Bioethics Committee with other more conservative ones. The strangest thing about the case is that a member of the committee voted in favour of the Law of Time Limits in 2009, and against it five years later.[21] The Attorney General's Office, on the contrary, was not inconsistent. It issued a report against the Law of Time Limits in 2009 and in favour of Gallardón's reform, with the odd qualification, in 2014.[22]

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[20] In 2009, the General Council of the Judiciary was unable to reach agreement to issue a report on the Law of Voluntary Termination of Pregnancy, since it was unable to achieve a majority of 11 out of a possible 21 votes. The president, Carlos Divar, chosen by José Luis Rodríguez Zapatero, added his vote to the nine conservative members to prevent the report approved by the studies committee from going ahead, supported by another nine progressive members and the writer of the report, Margarita Uría, chosen by the PNV. The member from CiU, Ramon Camps, abstained. It is a historic circumstance, since it is the first time in 29 years that the CGPJ has not reported on a law (José A. Hernández, *El País*, Madrid, 23 July 2009).

[21] Spanish Bioethics Committee (2009): Opinion about the bill for the Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy. (2014) Report on the draft bill of the Organic Law for the Protection of the Life of the Unborn Child and the Rights of the Pregnant Woman.

[22] The Prosecution Advisory Board is made up of 12 members. The death of a member from the progressive sector, the attorney Rafael Valero, meant that the six members elect of the conservative Public Prosecutors' Association could issue a report opposed to the Law of Voluntary Termination of Pregnancy. The president of the Prosecution Advisory Board, Cándido Pumpido, the deputy attorney and three members elect of the Progressive Union of Members issued an alternative report, that

Despite the conformity of the judges' governing body, of the new Spanish Bioethics Committee, and of the Prosecution Advisory Board, the proposal was met with huge opposition and protest, even from the ranks of the Partido Popular, as it would be taking Spain back to the clerical paradigm of the years of the Franco dictatorship. This full-frontal social rejection forced it to be halted, and the minister resigned, feeling that his authority had been undermined by the Prime Minister, Mariano Rajoy (September 2014).

Since then, Christian democrat Mariano Rajoy's tacit strategy has been to wait for the Constitutional Court to rule on the appeal lodged by members of his party, something that has still not happened.

4.2.7. A controversial matter: the consent of minors

One of the issues that generated the most political and social debate in the period when the new law was passing through parliament was the question of the minor's autonomy that had to be acknowledged with regard to the possibility of her deciding for herself to voluntarily terminate the pregnancy. One must remember that in Spain the Law of Patient Autonomy grants minors the power to decide for themselves with respect to their medical treatment from the age of 16,[23] except for participation in clinical trials, abortion and assisted reproduction.

The decision to have an abortion is, nevertheless, a very controversial matter that shows up many of the differences between words and deeds, and the most widespread and inconsistent cases of social hypocrisy with regard to the freedom of minors and ideas about parental authority and its limits.

The abovementioned *Document* of the Bioethics and Law Observatory had already talked about this, in 2002.[24] As we see in its conclusions, the Observatory's Opinion Group proposed the following:

> In the case of underage women, since they present special risks, it is necessary for: *a*) the validity of the consent of adolescents who are capable of understanding what they decide in the prescription of contraceptives, to be accepted;

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is, a dissenting opinion. With it, the Board was split (six to five). (María Peral, *El Mundo*, 24 June 2009.)

[23] Law 41/2002, of 14 November, basic regulator of patient autonomy and of rights and responsibilities in matters of information and clinical documentation.

[24] Bioethics and Law Observatory *Document on Sexual and Reproductive Health in Adolescence,* by Casado and Ros.

> *b*) relevant measures to be adopted so that their access to the different methods of contraception, including the morning after pill, is real; *c*) in the legal instances of voluntary termination of pregnancy, the validity of the consent of the minors who are capable of understanding what they decide and its consequences should be accepted.
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> The law should arbitrate the necessary measures to ensure the validity of the consent given by minors aged between 16 and 18, given that the current healthcare legislation establishes that from the age of 16 minors can give consent personally without the need to resort to their legal representatives. Between 12 and 16, the minor will be able to take a decision herself if she is mature enough to understand the scope of the intervention on her health, although the parents and legal representatives must be heard.
>
> In the event of a dispute arising, the proper mediation by experts must be actively encouraged, or by an external committee, who will act as mediators between parents and adolescents, so that the decision is taken with the maximum consensus between the minor and her parents or legal representatives, with the minor's interest always taking precedence.

The law we are analysing partially included this proposal, and article 13, section 4, established that:

> In the case of women aged 16 and 17, consent for the voluntary termination of pregnancy corresponds exclusively to them in accordance with the general regime applicable to adult women. At least one of the legal representatives, father or mother, persons with parental authority or guardians of women of this age must be informed of the woman's decision. This information will not be necessary when the minor claims with good reason that this will cause her a serious conflict, due to the certain danger of intra-family violence, threats, duress, battering, or there is a situation of upheaval or distress.

The wording of the article is a good example of the poor legislative technique used — or the lack of conviction in the legal decision adopted — that characterizes the new law: on one hand, in the first paragraph, autonomy was granted from the age of 16; then in the second paragraph it was limited, thus infringing the confidentiality of the doctor/patient relationship by requesting information from parents or guardians; finally, in the third and last paragraph, the minor only had to claim family strife and that was enough to exempt it from the requirement. What ought to have been clearly established was subject to an oscillation that moreover left a margin for interpretation so wide that it was not clear in what sense it was established, in practice, who determines what degree of conflict is required nor how the grounds for the minor's claim are decided.

It is an especially regrettable matter, since the legislators could have supported their decision with rulings already in existence in our own context, some of them very relevant in this respect such as, for example, the report by the Bioethics Advisory Committee of Catalonia to which we referred previously. This report proposes that the updating of the regulation of voluntary termination of pregnancy must envisage that the minor aged between 16 and 18 is considered capable, in principle, just as she is in other medical and healthcare situations. Thus, the pregnant woman aged between 16 and 18 could give her own consent to the termination of the pregnancy, and the woman's consent (whether a minor or not) would only be granted through a representative when she was clearly unable to make decisions, in the opinion of the medical team attending her as is the general rule. This clinical diagnosis would have to be reasoned and personalized, and be recorded in the corresponding clinical record. It is even recommended that it be made collectively and with the help of the clinic's ethics committee. Aside from this, only in the case of serious danger, in a doctor's opinion, should the minor's parents or representatives be informed; nevertheless, the necessary support and accompaniment should be provided and a period of reflection be proposed for the actual termination and to suggest to them the advisability of informing parents, guardians or, where appropriate, a trusted adult who may be able to help her in this situation: sharing the decision with someone the minor does not wish to must not be imposed. In the opinion of the Committee, formulas must be provided that, in practice, increase the accompaniment of the minor who decides to terminate a pregnancy, as well as the certainty of the professionals who have to perform it and the tranquillity of society with respect to it, but the self-determination of the person, free, informed and competent, should always be respected and encouraged.

If this regulation was in itself insufficient, the situation has got worse with the reform introduced by the Partido Popular. As we have said, the repeal of the Law of Voluntary Termination of Pregnancy failed, but that did not prevent them from reforming, probably to try to appease the most reactionary sectors of their party, the precept that we commented on.

And so, in 2015 Organic Law 11/2015, of 21 September, was published to reinforce the protection of minors and women with judicially modified capacity in the voluntary termination of pregnancy, which regulated this matter in the following way:

> For the voluntary termination of pregnancies of minors or persons with judicially modified capacity, besides the expression of their wishes, the *express consent of their legal representatives* will be necessary. In this case, any disputes arising with regard to the consent by the legal representatives will be resolved in accordance with the provisions of the Civil Code. [The italics are ours.]

The consequence of this reform is that in order for a minor to have an abortion she must have not just information, but also the specific consent of her parents. If there is a conflict between the wishes of the minor, who wants to have an abortion, and her parents, who are opposed to it, the matter will be settled in court following the general rules. One of the problems with this pseudo-solution is that the legal time limits for abortion are very short (14 weeks from conception) and Spanish justice is quite slow, whereby, with the system of tests, appeals, reports, and so on, it may simply be unfeasible to fulfil the minor's wish to terminate her pregnancy.

Besides, the reform was done indirectly, since the law of 2015 modified the Law of Voluntary Termination of Pregnancy, deleting the paragraph that allowed minors to have an abortion without their parents' consent, and it delegated the regulation of this matter to Law 41/2002, of 14 November, which regulates patient autonomy, where the paragraph that we have just commented on was introduced (which is an ordinary law and not an organic law).

As we can observe, the title of the law, and the reform itself, continues the paternalistic paradigm that inspired Gallardón's failed reform. Thus, the law is published to "reinforce the protection of minors", as if there were no other way of protecting them than leaving such a personal decision to their parents, when the problem is often precisely the family. Moreover, ultimately, if the matter is taken to court, a judge has to decide, with who knows what criteria, and so it will depend on his or her ideology.

4.2.8. An outstanding matter: conscientious objection

A matter that remains to be settled in Spanish law is the establishment of a clear regulation of conscientious objection by healthcare personnel, allowing them on one hand to exercise their right to ideological freedom, of which conscientious objection is a part, at the same time ensuring that users of the health system receive the services they are entitled to.

The case of abortion is one where objection is frequently present. The new law makes a brief and, in our opinion, imprecise reference to the matter in article 19.2,[25] so it would be advisable for the question to be developed in detail in a specific law.

The Bioethics and Law Observatory's *Document on Conscientious Objection in Healthcare*[26] made contributions that could be taken into account in a possible development of the law. The proposal acknowledged the possibility of conscientiously objecting, given that it is consubstantial to democratic societies that their members can disagree with the legally established general rules. For practical purposes it should be stated that conflict does not arise in issues accepted generally, but it emerges in controversial issues, difficult cases or open problems, for which there is no unambiguous solution. In healthcare especially, the conditions for objection must be established in such a way that they ensure it can be practised and, at the same time, that they meet the requirements for the necessary social transparency and for the special requirements of tempo in healthcare to be reflected — that is, so that treatment is not unfairly delayed. In short, the aim is to regulate the exercise of objection practically and to speed up the procedures for the service to be provided by another non-objecting professional.

Conscientious objection is, in our legal system, the expression of the fundamental right to ideological freedom, established in art. 16.2. of the Spanish Constitution. Confrontation appears when the exercise of conscientious objection, derived from the right to ideological freedom, has consequences that affect the constitutional rights of third parties, as in the case of receiving legally established healthcare services. If the exercise of ideological freedom comes into conflict with professional responsibilities, the problem must be resolved taking into account the principle of proportionality through the appropriate consideration of its adaptability to means, ends and consequences. Under no circumstances can freedom be understood as an absolute right, since the limits of one person's exercise of freedom are a third party's freedom and

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[25] Article 19.2. Measures to guarantee the provision of healthcare services.

2. The healthcare service for voluntary termination of pregnancy will be performed in hospitals in the public health service or associated with it. The healthcare professionals directly involved in voluntary termination of pregnancy will have the right to exercise conscientious objection provided access to and quality of the service is not affected by the exercise of conscientious objection. The rejection or refusal to perform termination of pregnancy for reasons of conscience is always a personal decision by healthcare personnel directly involved in the performance of voluntary termination of pregnancy, which must be expressed beforehand in writing. In any case the healthcare professionals will dispense suitable treatment and medical attention to the women who need it before and after undergoing a termination of pregnancy.

[26] See the Bioethics and Law Observatory's document on *Conscientious Objection in Health Care,* by Casado and Corcoy, the content of which is summarized in this chapter.

their right to equal treatment. Not even from positions that regard freedom as a priority is it possible to deny that people who work in the public health service are obliged to perform the duties that are entailed in the state's responsibility to protect health. Therefore, specifically with respect to abortion, it is proposed that the essential limit of conscientious objection by healthcare personnel should be the possibility of providing the service, and the exercise of it must meet certain requirements. Conscientious objection by a healthcare professional may cause the patient harm, so it can only be accepted when it does not restrict mandatory healthcare. The *Document* makes it clear that it is the public authorities' duty to establish a system that makes the exercise of freedom of conscience and the reception of healthcare possible at the same time.

It is, then, advisable to regulate the way in which healthcare personnel declare conscientious objection through a document that explicitly states which specific practices it affects, so that the healthcare manager can suitably organize the patients' care, since with each case of conscientious objection patients' proper care should always be ensured so that they may effectively exercise their rights. Therefore, hospitals and clinics must furnish the necessary means for the legally established services to be provided and, at the same time, provide the proper channels for workers to exercise their right to object; they must also establish a set of requirements to make sure that the objector really does have the convictions they claim to have. The possibility must be accepted of unexpected conscientious objection and also partial conscientious objection, which may also be unexpected, and which occasionally arises in extreme cases with respect to the performance of abortions.

Conscientious objection must be declared explicitly and the conditions, requirements and formalities, and the time limits to be able to exercise it, must be established. Conscientious objection may only be exercised due to behaviours that are effectively and directly affected by the beliefs on which objection is based. The formalization of the declaration of conscientious objection must be included in a register of the healthcare institution where it takes place. This register, insofar as its contents affect the right to privacy, must be protected in accordance with the current organic law of data protection.

4.2.9. Sexual health

The termination of pregnancy has obscured the fact that the law also regulated, for the first time in Spain, important questions referring to sexual health. Thus, article 2.b includes the definition of sexual health provided by the World

Health Organization: "Sexual health: the state of physical, mental and socio-cultural well-being in relation to sexuality, which requires an atmosphere free of coercion, discrimination and violence", establishing a series of measures that we shall divide into three levels:

1) Measures for the population. The law establishes as rights access to information and reproductive education, universal access to the services and programmes on this subject, access to safe and effective methods that make it possible to regulate fertility, and the elimination of all forms of discrimination, paying special attention to persons who have some type of disability.
2) Measures for the public authorities. The law establishes as an obligation of the public authorities the provision of "comprehensive healthcare" services, adopting the necessary measures so that the population can gain access to family planning through the incorporation of "fourth-generation contraceptives", and attending to women and their partners during pregnancy, birth and postpartum.
3) Measures for healthcare personnel. The law establishes the need to train sexual and reproductive healthcare professionals, before they start working in healthcare centres and through continuous training programmes.

However, this progressive regulation has been obscured by the clash with reality in which we are immersed. A good example is what has happened with the Morning-After Pill and pharmacies, which in Spain are private companies to which the state grants the monopoly of drug dispensation. That is, they are private bodies that exercise semi-public functions, without being government civil servants (somewhat similar to the case of notaries). Moreover, it is necessary to stress that in many places in Spain there is only one pharmacy, or very few, depending on population size, whereby conscientious objection by the local pharmacist could make the population's right to have access to fourth-generation contraceptive methods unviable.

As we said earlier, the Bioethics and Law Observatory published a *Document on Conscientious Objection*. In this document we recommended the need to bear in mind that pharmacies, as "private healthcare establishments providing a public service and subject to healthcare planning", must take steps to ensure the administration of medications and healthcare products to which users are entitled, in such a way that the conscientious objection that pharmacists may hypothetically exercise is not detrimental to the service that pharmacies must provide to citizens. For this, planning measures for the purpose of ensuring the provision of the service should be outlined.

The surprising sentence of the Spanish Constitutional Court that we commented on came in this context of anomie. The Junta de Andalucía administratively sanctioned a pharmacist because he did not stock condoms and the Morning-After Pill for reasons of conscience. After exhausting the administrative channels and the courts, the pharmacy managed to get the Constitutional Court to partially admit its appeal for protection, in the following sense:[27]

1) The Constitutional Court considered that the sanction for not stocking the Morning-After Pill infringed the pharmacist's right to conscientious objection. The fact that the pharmacy was in the centre of the city of Seville, which would allow hypothetical users to go to another one nearby, was one of the aspects that the court took into account (despite not checking if it was indeed so). Moreover, as if that was not enough, the court argued that the pharmacist was sanctioned not for refusing to supply this pill, but for not having the minimum stock necessary to dispense it if someone asked for it.
2) The Constitutional Court considered that conscientious objection did not allow the pharmacist to refuse to dispense condoms, whereby it agreed for the sanctioning procedure to be restarted so that the Junta de Andalucía could process it again (it would probably have timed out).

The sentence has received a great deal of criticism, as it represents a notable regression on the subject of fundamental rights, it contradicts itself (why yes to the pill and no to condoms?), and it contradicts other sentences, not just of the Constitutional Court, but also of the European Court of Human Rights, for example in Pichon and Sajous v. France, which in an identical situation denied conscientious objection to pharmacists.

The sentence in fact generated three dissenting opinions, with arguments that could not be more caustic, something uncommon among magistrates of the same court. These opinions state that the sentence is "a pronouncement with a marked ideological bias" (Valdés, Dal-Ré), "To pretend that obedience of the law may depend on everyone's moral code is a clumsy caricature of the right to conscientious objection" (Ollero Tassara) and "Today it is the dispensation of the contraceptive pill, tomorrow it could be obligatory vaccination, or the obligation to pay taxes, or many other things, affected by the refusal to do one's legal duty by appealing to the right to conscientious objection, adapt-

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[27] Sentence of the Constitutional Court no. 145/2015, of 25 June. RTC 2015/145.

ed to the wishes of whoever employs objection, without the need for legal regulation of the matter" (Asua Batarrita).

4.2.10. The outcome of the law

The inclusion in the same law of public policies on sexual and reproductive health and the termination of pregnancy has unquestionably been a success. Uniting educational, social and healthcare measures and treating abortion as a medical act is wholly desirable and responds to a long-standing demand. Nevertheless, one must bear in mind that — given the vague wording of many precepts — we will have to wait for more time to pass before we can see how effective the application of the law has been. With the added matter, in the case of Spain, that the transfer of powers over healthcare to the different autonomous communities has so far generated clearly evident territorial inequalities in access to safe abortion, which come on top of all the other already known and usual ones that abortion entails. Furthermore we must not forget the insecurity generated by not knowing what the Constitutional Court is going to decide, especially with the precedent that we have just mentioned about the Morning-After Pill. In this respect, it is interesting to quote the assessment made by Betlem Cañizar, Marisa Fernández and Montserrat Cervera:

> Despite incorporating improvements with respect to the law in effect up to now, for many feminists and areas of society, the new law does not completely resolve the lack of legal protection of women and doctors in relation to this practice […]. From the strictly legal point of view, we can say that the result of this legislative change has been very limited since, despite the improvements, it has missed the opportunity to implement a pioneering legal idea. Many of the law's initial intentions have turned into generic declarations of principles that do not correspond to the regulatory part. Influenced by more conservative attitudes, the proposal does not recognize rights, it does not legalize abortion (it is still in the Criminal Code), and, moreover, it limits women's right to decide freely and responsibly about maternity. Seen from a possibilist perspective, of course, the majority of women will legally be able to have an abortion without being forced to give a reason, given that around 88% of abortions take place before week 12 of gestation, a situation that enters within the terms of the new law. But, as we said, from a perspective of the acknowledgement of women's rights and autonomy, the result is more limited.[28]

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[28] See the paper by Betlem Cañizar, Marisa Fernández and Montserrat Cervera, *Sin Permiso*, 28 February 2010, at www.sinpermiso.info/texts/index.php?id=3138.

In sum, the law, with a reasonable criterion in the context, increases the protection of the foetus with the gradual possibilities of being viable. Between weeks 14 and 22 of gestation a medical ruling proving the existence of serious danger to the woman's life or health or of anomalies in the foetus is required. However, we insist in stressing that on this point the law is more restrictive than the previous one, which did not establish any time limit in relation to the risk for the woman's health. Lastly, nor does the law clearly resolve the problems entailed in the late detection of certain foetal anomalies that are discovered after week 22 of pregnancy and give rise to very critical situations.

5. Towards a European canon[29]

Europe is subject to the dialectical tension that arises when secular attitudes clash with ultra-religious ones, not necessarily Christian (for example, in Turkey the man's consent is necessary for the woman to be able to have an abortion). From the point where these two fault lines meet, from the silence of European laws on the controversial points and the ambiguity of the European high courts, there emerge interpretations that support one position or the other. Through reading different reports, rulings, recommendations and sentences, we have chosen a series of thematic areas that may be useful when it comes to understanding the complex situation in Europe.

1) *Respect for women's autonomy.* Both the Council of Europe and its Parliamentary Assembly have made the case for member states to respect women's autonomy and to ensure that, if an abortion is performed, it should be done without endangering the woman and she should have the necessary information.[30] These bodies maintain that prohibition does not reduce the number of abortions, but it sends these practices underground, with the resulting appearance of "abortion tourism" and the increased risk for women's physical and mental health[31] and female mortality.

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[29] This heading is part of the subject "La interrupción del embarazo en Europa", part of the materials of the master's degree in Bioethics and Law taught at the Bioethics and Law Observatory, University of Barcelona, whose author is Manuel Jesús López Baroni.

[30] Report no. 11.537 of the Council of Europe's Advisory Committee on Equal Opportunities for Men and Women. 17 March 2008; Resolution 1607/2008, of 16 April, of the Parliamentary Assembly of the Council of Europe, entitled *Access to Safe and Legal Abortion in Europe.*

[31] This last idea comes from Resolution 2001/2128, of 6 June, of the European Parliament (EU), on Sexual and Reproductive Health and Rights.

2) *Law of time limits*. The Parliamentary Assembly of the Council of Europe recommended establishing a system of time limits in Europe, as it is the most effective policy for ensuring women's autonomy.[32] Along the same lines, the European Parliament required member countries of the European Union to legalize abortion, "in order to make it more accessible to all and thus eliminate the risks of illegal practices".[33]

In Europe the system of time limits, with 12 weeks to be able to terminate pregnancy, 14 in the case of Spain, is the majority model. Other countries, like Finland or Great Britain only allow abortion in certain circumstances, but these are wide-ranging.[34]

3) *Formal requirements for the termination of pregnancy*. The Parliamentary Assembly of the Council of Europe has publicly shown its concern about the fact that in many European countries such strict formal requirements are established that, in practice, they prevent, block or delay access to a safe and accessible abortion (repetitive medical reports, the lack of doctors willing to per-

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[32] Resolution 1607/2008, dated 16 April 2008, of the Parliamentary Assembly of the Council of Europe, entitled *Access to Safe and Legal Abortion in Europe*.

[33] Resolution 2001/2128, of 6 June, of the European Parliament (EU), on Sexual and Reproductive Health and Rights.

[34] Abortion has been legalized in most countries in the European Union. Austria, Belgium, Bulgaria, the Czech Republic, Denmark, Estonia, France, Germany, Greece, Hungary, Latvia, Lithuania, Norway, Romania, Slovakia, and Switzerland have a law of time limits up to 12 weeks of gestation. The period extends to 24 weeks in the Netherlands, 18 weeks in Sweden and 90 days in Italy. On the contrary, in Portugal it only reaches ten weeks. Once these limits have been passed, some countries continue to allow abortion due to specific indications and within new limits. Up to the second trimester, it is accepted when danger for the mother's life is indicated in Austria, Denmark, Slovakia, France, Hungary, Luxemburg, Norway, the Czech Republic, Romania and Switzerland; when the mother's life is in danger in Austria, Denmark, France, Luxemburg, Norway and Switzerland; due to malformation of the foetus in Austria, Denmark, Slovakia, France, Luxemburg, Norway, the Czech Republic and Romania; or due to rape in Slovakia, Hungary, Luxemburg, Norway and the Czech Republic. In the Czech Republic "medical reasons" are also added, in Hungary in the event of a "serious crisis situation", and in Austria it is allowed up to the second trimester for girls under the age of 14. In Greece abortion is accepted in cases of rape up to week 20 and due to malformation of the foetus until week 24. In the United Kingdom there is a law of indications whereby it is possible to abort up to week 24 due to danger because of the mother's physical or mental health or financial and social problems. In countries such as Austria, Belgium, Denmark, France and the United Kingdom there are no time limits for abortion when there are risks of malformations in the foetus. Nor when there is serious risk for the life of the mother in Belgium, France, Luxemburg and the United Kingdom and due to "medical reasons" in Germany. CASADO; M.; CORCOY, M.; ROS, R.; ROYES, A. (coords.). *Document on Voluntary Termination of Pregnancy.* Bioethics and Law Observatory. University of Barcelona, April 2008.

form it, excessive waiting periods, the lack of suitable facilities, and so on).[35] In this respect, the European Court of Human Rights established that:

> […] although the state enjoys a broad margin of appreciation for defining the circumstances in which it authorizes abortion (sections 321-238 supra), once the decision has been made, the corresponding legal framework must "show a degree of consistency and make it possible to suitably attend to the different legitimate interests at stake in accordance with the obligations derived from the Convention" (S. H. et al. v. Austria (ECHR, 2010, 56), no. 57813/2000, sec. 74, 1 April 2010).[36] […] once the legislator has decided to authorize abortion, the corresponding legal framework should not be conceived in such a way that it actually limits the possibility of gaining access to this intervention.[37] […] the Convention aims to guarantee not just the rights that are theoretical or illusory but also those that are practical and effective […] the state has a positive obligation to create a procedural framework that allows a pregnant woman to effectively exercise her right to a legal abortion.[38]

In other words, countries are free to authorize abortion or not, but once this is a legal reality, formal and/or factitious obstacles cannot be put in place that make it unfeasible.

In this respect, the European institutions have rejected the policies of indirect boycotting, like, for example, the "Mexico City Policy" introduced by President Ronald Reagan of the USA in 1984, suspended in 1993, and reintroduced by George W. Bush in 2001 (it is thus called due to the place where it was proclaimed for the first time).[39] They are actions aimed at cutting or eliminating the public subsidies received by the non-governmental organizations which, as a last resort, send women to abortion clinics.

The European Parliament, faced with the application of this kind of policy in Central and Eastern Europe, requested the European Commission to make up for these budgetary shortages by subsidizing these organizations directly,[40] so that they could continue to offer guidance to women.

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[35] Resolution 2001/2128, 16 April 2008, of the Parliamentary Assembly of the Council of Europe.

[36] A, B and C v. Ireland. Grand Chamber. Sentence of 16 December 2010, ECHR/2010/116.

[37] Tysiac v. Poland. Sentence of section four, 20 March 2007, ECHR, 2007/20.

[38] ECHR. P. and S. v. Poland. Sentence of the European Court of Human Rights, of 30 October 2012. ECHR/2012/96.

[39] Also called the global gag rule. Its effects vary, covering family planning policies or permitting public funding in the case of rape or risk for the mother. In January 2017, President Donald Trump reintroduced this doctrine (Federal Register/vol. 82, no. 15, Wednesday, January 25, 2017, Presidential Documents, 8495), which had been suspended during the Obama presidency.

[40] Resolution 2001/2128, of 6 June 2002, of the European Parliament on Sexual and Reproductive Health and Rights.

4) *Importance of sexual and reproductive health policies*. The Council of Europe[41] and its Parliamentary Assembly[42] each issued documents urging the promotion of effective sexual and reproductive health policies to prevent pregnancy, as it has been shown that they reduce the number of abortions. The Parliament of the European Union, taking the matter further, advocated the provision of free or inexpensive contraceptives and sexual and reproductive health services to the most underprivileged groups, such as young people, ethnic minorities and social outcasts, encouraging emergency contraception (the Morning-After Pill) and allowing it to be distributed without a prescription at reasonable prices.[43]

A point of reference for Europe is the French Veil Law (Law 75/17, of 17 January 1975), since it "included the regulation of VTP in the public health code, considering that this intervention, which affects women particularly, could not be subjected to a regime of healthcare guarantees different from all other interventions, when it is performed under the established legal terms" (Bach et al., 2014).[44] The opposite of this model is Poland, where there is no sexual education, and Ireland, where family planning is only funded if "natural methods" are used. Moreover, the three bodies mentioned have insisted that the idea must not be transmitted that abortion is just another method of contraception.[45]

Lastly, European Parliament Resolution 30.172/92, of 8 July 1992, approving the European Charter of Children's Rights, establishes that children must be provided with education on the subject of sex, as well as the necessary medical care with the inclusion of birth control measures, while respecting philosophical and religious convictions. In this respect, the Spanish Council of State summarized the doctrine of the European Court of Human Rights (sentences 1976/5, of 7 December, Kjelsen, Busk and Pedersen v. Denmark, and [...] v. Spain, ECHR JUR/2006/242834, of 25 May 2000) in the following way:

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[41] Report no. 11.537 of the Council of Europe's Advisory Committee on Equal Opportunities for Men and Women (17 March 2008).

[42] Resolution 1607/2008, dated 16 April 2008, of the Parliamentary Assembly of the Council of Europe.

[43] Resolution 2001/2128, of 6 June 2002, of the European Parliament on Sexual and Reproductive Health and Rights.

[44] Report on the draft bill of the Organic Law for the Protection of the Foetus and the Rights of the Pregnant Woman. Dissenting opinion on the report passed by the plenary session of the General Council of the Judiciary in session of 13 June 2014, formulated by Roser Bach Fabregó, Mar Cabreras Guijaro, Victoria Cinto Lapuente, Álvaro Cuesta Martínez, Clara Martínez de Careaga García, Rafael Mozo Muelas, Concepción Sáez Rodríguez and Pilar Sepúlveda García de la Torre.

[45] In line with the Declaration and the Programme of Action of the United Nations Conference on Population and Development. Cairo, 5-13 September 1994.

> *a)* Parents do not have a right to absolutely veto children's sex education, just as they cannot deprive them of generic education; *b*) the instruction must be "objective and scientific" and "exclude any tendency to indoctrination", so it must not "extol sex or incite pupils to begin practices prematurely that are dangerous for their equilibrium, their health or their future, or reprehensible to parents"; *c*) sex education must be provided "delicately" paying special attention to the children's age and gender; *d*) if the subject taught is "excessively categorical and explicit" and, consequently, "harmful for children who are vulnerable because of their age", then it must be banned, as occurred with a sex education text withdrawn from circulation by the British authorities (Handside v. UK, 7 December 1976, 1976/6). [The summarized adaptation of their arguments is ours].[46]

5) *Legal consequences for women*. The Parliament of the European Union called upon the governments of member states and candidate countries to refrain from prosecuting women who had had an illegal abortion[47] (in Spain, for example, this policy is only half implemented, as the woman is not prosecuted if the formal requirements for an abortion are lacking, but she may be found guilty if an abortion is performed outside the cases or periods permitted by the law). In this respect, the Programme of Action approved at the Fourth World Conference on Women (Beijing, 1995) referred to section 8.25 of the Programme of Action of the ICPD held in Cairo in 1984, where there was an undertaking by governments to consider reviewing laws that envisaged punitive measures against women who had had an illegal abortion.

6) *The right to abortion in European law*. Neither the European Convention on Human Rights,[48] nor the European Convention on Bioethics,[49] nor the Charter of Fundamental Human Rights of the European Union said anything about the termination of pregnancy, which has led to contrasting interpretations. This silence has generated the following positions:

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[46] Council of State. Ruling 1384/2009 on the draft bill of the Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy (17 September 2009).

[47] Resolution 2001/2128, of 6 June 2002, of the European Parliament on Sexual and Reproductive Health and Rights, in accordance with the Declaration and the Programme of Action of the United Nations' Fourth World Conference on Women (Beijing, 15 September 1995).

[48] Convention for the Protection of Human Rights and Fundamental Freedoms, Rome (4 November 1950).

[49] Convention of 4 April 1997 for the Protection of Human Rights and Dignity of the Human Being with regard to the Applications of Biology and Medicine, Oviedo, 4 April 1997. Ratified by Spain through instrument of ratification of 23 July 1999. RCL 1999\2638, this Convention came into force on 1 January 2000.

6.1. The movements opposed to the termination of pregnancy interpret this legal loophole in the sense that in Europe there is no right of access to abortion, nor to performing it.[50] The Spanish Council of State, reporting on the Law of Voluntary Termination of Pregnancy of 2010, argued that "the right to abortion" was "something unknown in the legal systems of countries near to us that are liable to be taken as models, […] that it is not even mentioned in the international instruments relative to women's rights (see Resolution 48/104, of 20 December 1993, article 3) and whose formulation is groundless in our legal system".[51]

Nevertheless, the reality is more complex, since what happens is simply that, faced with the absence of a particular law on this matter, the European Court of Human Rights has decided not to rule on it, either one way or the other ("Therefore, the Court must not enquire, in this case, into whether the Convention guarantees the right to abortion." Tysiac v. Poland), and in fact, the Council of State's report that we mentioned earlier acknowledges this fact: "the European Court of Human Rights has refused to issue a ruling." However, once again we must qualify this, because although it is true that the court does not acknowledge a specific right to abortion, it is aware that in practice numerous countries recognize that women have this possibility, whence it infers that the protection of the unborn child cannot be absolute in Europe:

> Unconditional respect for the protection of prenatal life or the idea that the rights of the future mother are less important *does not automatically justify, by virtue of the Convention, a prohibition of abortion based on the wish to protect the life of the unborn child*. Contrary to what the (Irish) government maintains, based on certain international declarations, […] the regulation of the right to have an abortion does not pertain exclusively to the contracting states either. […] the Court must determine if the Irish state's prohibition of abortion for reasons of health or welfare is compatible with article 8 of the Convention, based on the said criterion of just equilibrium, on the understanding that the state must be recognized as having a broad margin of appreciation.[52] [Our italics.]

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[50] Prosecuting Council's report on the Gallardón project. (Jean-Jacques Amy v. Belgium, ECHR.) Prosecuting Council's report on the draft bill of the Organic Law for the protection of the life of the unborn child and the rights of the pregnant woman. Eduardo Torres-Dulce Lifante, State's Attorney General, president of the Prosecuting Council (12 June 2014).

[51] Council of State. Ruling 1384/2009 on the draft bill of the Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy. 17/9/2009.

[52] A, B and C v. Ireland. Grand Chamber. Sentence, of 16 December 2010. ECHR/2010/116.

Lastly, on the question of the right to have an abortion, it is interesting to point out that the Spanish Council of State, taking into account the doctrine of the Spanish Constitutional Court and the European Court of Human Rights, proposed the following wording of the Spanish Law of Termination of Pregnancy:[53]

> This makes it advisable to qualify the confused, and therefore, controversial wording of article 12 of the draft bill consulted, referring, as we see later on, not to a right to have an abortion but to the healthcare services necessary for the voluntary termination of pregnancy. It is enough for these purposes to say "it is guaranteed" given that the expression "is acknowledged" is typical of constitutional declarations of fundamental rights. It would also be necessary, as alternative wording, to replace the present one with the following: "The voluntary termination of pregnancy is legal, performed in the conditions envisaged in this law that will be interpreted…".

The final wording of the Spanish Law of Voluntary Termination of Pregnancy of 2010 establishes the following:

> *Access to the voluntary termination of pregnancy is guaranteed* in the conditions that are determined in this law. These conditions will be interpreted in the most favourable way for the protection and effectiveness of the fundamental rights of the woman who requests the intervention, in particular, *her right to freely develop her personality*, to life, to physical and moral safety, to privacy, to ideological freedom and to non-discrimination. [Our italics.]

The conclusion that we can draw about the "right to have an abortion" is that the main European laws on the subject remain silent on this point and the European Court of Human Rights has not wished to give an express ruling, but that this is no obstacle for the legislation of a specific country to acknowledge as a subjective right the right to the voluntary termination of pregnancy, as has been the case in Spain. In the face of a situation of alegality, not illegality, there is nothing to prevent new rights from being acknowledged, and, as the European Court of Human Rights itself states:

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[53] Council of State. Ruling 1384/2009 on the draft bill of the Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy. 17/9/2009.

> The Court has already found that there is consensus among a substantial majority of the contracting states of the Council of Europe for the permission of abortion and that the majority of Contracting Parties have resolved, in their legislation, the conflicting rights of foetus and mother in favour of greater access to abortion.[54]

6.2. Every European country can freely regulate the issue of abortion (prohibit it, or accept a system of time limits or indications), it being the European Court of Human Rights' duty to judge this hypothetical regulation, taking into account two parameters, proportionality and consideration of the interests at stake. However, if a member state decides to regulate the termination of pregnancy, then "the legal provisions must, first and foremost, ensure that the pregnant woman's legal position is clear" (Tysiac v. Poland, ECHR, 2007/20).

In this respect, the European Parliament has pointed out that, while recognizing that the regulation of reproductive health is the competence of each member state, "the European Union can play a supporting role through the exchange of best practices".[55] Similarly, the Parliamentary Assembly urged member states of the Council of Europe to "examine, update and compare national and international policies and strategies of the member states of the Council of Europe relative to population, health, and sexual and reproductive rights".[56]

The importance of reciprocal influences in Europe can be observed in the sentence of the West German Federal Court of 25 February 1975, in which it stated that "according to established biological and physiological knowledge, human life exists from the fourteenth day after conception". It is the establishment of the 14-day rule as a precedent, which in turn is in line with the Warnock Report, that has legitimated the distinction between pre-embryos (under 14 days) and embryos (from that day on), and which in turn has made artificial reproduction and embryonic stem cell research possible in Europe. That West

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[54] P. and S. v. Poland. Sentence of the European Court of Human Rights, 30 October 2012. ECHR/2012/96.

[55] Resolution 2001/2128 of the European Parliament on Sexual and Reproductive Health and Rights, of 6 June 2002.

[56] As the European Court of Human Rights said (A, B and C v. Ireland), the Parliamentary Assembly pointed out that, while progress had been made after the Programme of Action of the International Conference on Population and Development in Cairo, 1994, "Nevertheless the results continued to be not very favourable with regard to school attendance, equity and equality between the sexes, infant and maternal mortality and morbidity, and universal access to sexual and reproductive healthcare services, including family planning and the services that perform safe abortions". For that reason, the ACPE urged member states of the Council of Europe to examine and compare funding to guarantee the comprehensive application of the ICPD's Programme until 2015.

German sentence also influenced the famous sentence of the Spanish Constitutional Court in 1985, which declared termination of pregnancy in the three typical cases (rape, malformation of the foetus and danger to the mother's health) to be constitutional.[57]

6.3. In Europe, when does human life begin? As the European Court of Human Rights clearly states, "one might search in vain in the legal and social systems of the contracting states for a uniform European concept of morality, in particular on the issue of knowing when life begins".[58] [...] "This jurisprudence was confirmed in the referenced Vo case (ECHR 2004, 52), in which the Court ruled that it was neither desirable nor possible to answer the question of whether the unborn child was a 'person', in the sense of article 2 of the [European] Convention [of Human Rights]." The consequence of this view is that the European court delegates to the different states the establishment of the exact moment when human life commences.

Lastly, the Spanish Council of State, in its report on the Law of Voluntary Termination of Pregnancy of 2010, remembered how the European Commission's European Group on Ethics in Science and New Technologies considered that in Europe two paradigmatic ideas were opposed to one another: "the one that considers that the embryo is not a human being, and therefore does not merit unlimited protection, and the other one according to which the embryo enjoys the moral status of every human being, and must, therefore, benefit from wide-ranging protection."[59]

6.4. Women's private life. Analysing the European Convention on Human Rights, the European Court of Human Rights has pointed out that, although article 8, like article 2, does not guarantee the right to have an abortion, the

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[57] The following sentences, together with a judicial decree, for the moment make up the constitutional jurisprudence on the status of the embryo and the foetus in Spain. Sentences of the Constitutional Court 53/1985, of 11 April, on the constitutional nature of the bill for the organic law to reform article 417 bis of the Criminal Code of 1973, for the legalization of abortion in certain cases; sentence 212/1996, of 19 December, on the unconstitutional nature of Law 42/1998, of 28 December, of donation and use of human embryos and foetuses; sentence 116/1999, of 17 June, on the unconstitutional nature of the Law on Assisted Reproduction Techniques; ruling of the Constitutional Court no. 90/2010, of 14 July, RTC\2010\90, which agrees not to suspend the application of the Law of Voluntary Termination of Pregnancy while an appeal on grounds of unconstitutionality lodged against the said law is being processed.

[58] ECHR. A, B and C v. Ireland.

[59] Council of State. Ruling 1384/2009 on the draft bill of the Organic Law of Sexual and Reproductive Health and Voluntary Termination of Pregnancy. 17/9/2009.

fact that a country prohibits abortion for health reasons does affect article 8, namely, women's right to privacy, whereby this specific prohibition could be legitimately examined by the court. It maintained that:

> The essential object of article 8 is to protect the individual against arbitrary interference by the public authorities. [...] Whereas the Court has declared that article 8 cannot be interpreted as a right to abortion, it has found that the prohibition of abortion when it is requested for health and/or welfare reasons comes within the sphere of the right to respect for one's private life and as a consequence of article 8 [...] the notion of private life in the sense of article 8 is applied to the decisions to be a parent and not to become one. [It refers to a case of rape. The clarification is ours.][60]

7) *The consent of minors*. In the case of the rape of a minor, her right to have an abortion takes precedence over her parents' opinion on the matter. Thus, in the case of a minor who wanted to have an abortion after being raped, the European Court of Human Rights considered the following:

> The Court acknowledges that in a situation of an unwanted pregnancy *the mother of a minor is not affected in the same way*. It is of the opinion that it cannot be considered that legal guardianship automatically confers on the parents of a minor the right to make decisions about the minor's reproductive options, because the minor's personal autonomy in this area must be taken into account.[61] [Our italics.]

If we compare it with the Gallardón reform, which we mentioned earlier, we can see that its proposal (that it should be a court of law that decides, and, if the parents are opposed to it, the parents' decision will be taken into account especially if the minor is 15 or younger) was contrary to the doctrine of the European court.

8) *Conscientious objection*. The Parliamentary Assembly of the Council of Europe established in a resolution that "no person, hospital or institution will be coerced, blamed or discriminated against for refusing to perform, authorize,

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[60] P. and S. v. Poland. Sentence of the European Court of Human Rights, of 30 October 2012. ECHR/2012/96.

[61] P. and S. v. Poland. Sentence of the European Court of Human Rights, of 30 October 2012. ECHR/2012/96.

participate in or assist in the performance of an abortion, euthanasia or any act that causes the death of a human foetus or an embryo for any reason".[62]

This resolution has been interpreted by the movements opposed to abortion as a reinforcement of the conscientious objection of healthcare personnel to cover not just those directly involved in the performance of the abortion (as established, for example, in article 19.2 of the Spanish Law of Voluntary Termination of Pregnancy of 2010), but also the staff that take part indirectly (anaesthetists, midwives, etc.). However, this interpretation should not be deduced from the literal tenor of the paragraph that we have cited, despite the dramatic nature of its wording ("the death of a human embryo"), given that the resolution simply encourages conscientious objection to be guaranteed, something that incidentally already appears in other European legal texts.

Moreover it is usually overlooked that, in section 2 of this same resolution, the Parliamentary Assembly emphasized the need to make the right to conscientious objection compatible with the right of patients to receive healthcare when necessary, and also the fact that the absence of specific regulation on this matter may disproportionately affect women, especially those who live in rural areas or lack financial resources. In this respect, the Spanish Law of Voluntary Termination of Pregnancy, of 2010, stresses that the right to conscientious objection must not prevent women from exercising their right to voluntarily terminate their pregnancy (Art. 19.2).

9) *The status of the embryo with regard to patents*. In 2011, the Court of Justice of the European Union issued a sentence that caused a great commotion, as it maintained that, "every human egg, after fertilization, must be considered a human embryo [...] bearing in mind that fertilization can initiate the process of development of a human being".[63]

This sentence has been used by movements opposed to abortion as an argument in their favour (for example, in a dissenting opinion by members of the Spanish General Council of the Judiciary.)[64] Nevertheless, nothing could be further from the truth, since the sentence was issued in the context of the

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[62] Resolution 1763/2010, of 7 October 2010, of the Parliamentary Assembly of the Council of Europe, on the right to conscientious objection in healthcare.

[63] Sentence of 18 October 2011. TJCE\2011\316.

[64] General Council of the Judiciary. Dissenting opinion of members Nuria Díaz Abad and Juan Manuel Fernández Martínez on the report on the draft bill of the Organic Law for the protection of the unborn child and the rights of the pregnant woman.

application of patents, specifically, of Directive 98/44/EC of the European Parliament and of the Council, of 6 July 1998, relative to the legal protection of biotechnological inventions.

Therefore, the sentence was intended to define which parts or elements of the human body may not be the object of biotechnological patents, specifically excluding the human embryo for the reason given above, in a context in which fragments of human DNA had begun to be patented in the USA. The sentence had nothing whatsoever to do with the termination of pregnancy in Europe or with embryonic stem cell research, also taken from embryos and legal in many European countries.

In sum, the situation of the voluntary termination of pregnancy in Europe reproduces the cultural, geographical, religious and ideological complexity of the continent, and for this reason we have been unable to show a single consistent and indubitable policy or law with regard to it.

Despite this, we can argue that in Europe: *a*) countries are free to decide whether or not to regulate the termination of pregnancy; *b*) the majority have opted for a system of time limits, following the recommendations of the Council of Europe and the European Union; *c*) the weight of the Catholic religion restricts, making it unviable, the termination of pregnancy in Ireland and Poland, despite the fact that their laws permit it in certain cases; *d*) the European Court of Human Rights has established that, once countries allow the possibility of having an abortion in their legislation, they must not prevent it indirectly by imposing unnecessary formal requirements or pressuring women; *e*) the court gives priority to a minor who has been sexually assaulted over and above the opinion of her parents, in the event that they are opposed to abortion; and *f*) lastly, the status conferred on the embryo by the Court of Justice of the European Union refers solely and exclusively to the impossibility of obtaining patents for it, without this in any way affecting the termination of pregnancy or embryonic stem cell research.

6. Recommended reading

Atienza, M.; González-Meneses, M. (2009). "Debate sobre el proyecto de nueva regulación del aborto." *Revista de Bioética y Derecho,* UB, no. 16, pp. 2-25.

Buisán Ezpeleta, L. (2009). "El plazo de las 14 semanas." *Página abierta*, no. 203 (July-August), p. 35.

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López Baroni, M. J. (2017). "La interrupción del embarazo en Europa." Materials for the master's degree in Bioethics and Law. Bioethics and Law Observatory. Barcelona: Edicions de la Universitat de Barcelona.

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5

Assisted Reproduction

1. INTRODUCTION[1]

Assisted reproduction techniques offer the possibility of being biological parents to people who, without the help of these biotechnological advances, would not be able to have children. In our context, these techniques are used to treat medical problems, and to respond to social demands and the personal situations of individuals or couples. Their use has led to a rethink on numerous issues that it was believed were established,[2] the concepts of paternity or maternity especially.

The widespread use of assisted reproduction techniques has made it necessary to come to terms with unprecedented situations, concepts and ideas, such as preimplantation diagnosis, genetic counselling, dissociation between genetic material and maternity, the possibility of mixing several people's DNA, and sex selection. In an atmosphere of widespread controversy in society, they are all in need of specific regulation. Furthermore, assisted reproduction techniques have opened the doors to research subjects, inconceivable until very recently, totally unconnected to reproduction, such as therapeutic cloning or the use of embryonic stem cells to obtain all kinds of human body cells.

As is usually the case in bioethics, the advantages that they bring come with problems that are hard to define. For example, the interrelationship between the new reproductive possibilities and the existing laws in Spain has given women more autonomy when it comes to being mothers, even without the need for a male, but as a side effect it has also generated new forms of pres-

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[1] This chapter is based on the previous articles by CASADO, M. (1997) "Reproducción humana asistida: los problemas que suscita desde la bioética y el derecho", *Papers* 53, pp. 37-44, and LÓPEZ BARONI, M. J. (2015) "*Bioética y Multiculturalismo: Políticas Públicas en España (1978-2013). El hecho cultural ante la revolución biotecnológica*". University of Barcelona, pp. 289 and 290.

[2] Unless otherwise stated, when talking about assisted reproduction reference is made to artificial insemination (homologous, with material from the couple, and heterologous, with material from the donor) and in vitro fertilization and its different techniques.

sure, the most extreme being the objectification and commercialization of their bodies.[3]

Spain was one of the first countries to have specific legislation on the subject, in 1988, despite being heavily criticized at the time. Nevertheless, this law represented very important progress because, by regulating in detail the use of assisted reproduction techniques, it gave healthcare personnel, clinics and users essential legal certainty. In addition it contributed to the legitimization and normalization of their use, which generated a favourable perception in society, due to the guarantee that this law represented, because, as is well known, the law fulfils the function of legitimizing the behaviours that it regulates and does not prohibit.

Moreover, this law placed us in the orbit of the more advanced countries culturally close to Spain, since it followed the guidelines set by the Council of Europe since 1978 and those established in several international reports. Among these documents one must mention those by the Warnock Committee (United Kingdom, 1984) and the Benda Committee (West Germany, 1985), the immediate precedents of the Palacios Report, approved by the Spanish parliament in 1986 and which paved the way for Spain to become scientifically and socially modern.

2. Regulation of assisted reproduction techniques in Spain

As we have said, human assisted reproduction was first regulated in Spain in the 1980s through Law 35/1988, of 22 November, of Assisted Reproduction Techniques, and Law 42/1988, of 28 December, on the Donation and Use of Human Embryos and Foetuses or of their Cells, Tissues and Organs.

With these two laws the aim was to protect the fundamental rights of parents, children and donors of genetic material, and those of surrogate mothers, inspired by the principle of the protection of the child rather than by the couple's point of view. Thus, issues were regulated such as homologous artificial insemination, with special consideration given to it post mortem, heterologous artificial insemination (by donor) performed in stable heterosexual couples and in single women, in vitro fertilization in its different cases, the matter of the legal

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[3] See the interesting analysis by G. Sarrible in "The Not So Sacred Image of Motherhood", in *Young Women and Life Choices* (by various authors), a monographic study carried out under the auspices of UNFPA, published by Sid Occasinel Publication Series, Rome, May 1992.

status of embryos, surrogate motherhood, the filiation of children born using these techniques, the characteristics of the donation of genetic elements and the different responsibilities deriving from assisted reproduction techniques.

The question of paternity was resolved by following a criterion of formal adjudication of paternity, derived from having previously agreed to it in writing — in an authenticated document — when accessing the techniques. It is interesting to point out that, after centuries of struggling to be able to establish the biological father's paternity, claiming for it the free investigation of paternity,[4] the material criterion gave way to the formal one with assisted reproduction techniques, as also occurs with adoption. Maternity is established by giving birth, a physical event that determines filiation whatever the origins of the genetic material. With regard to donors, the law established the principle of gratuity, making the clinic responsible for the health data, as anyone could be a donor. Additionally, the law allowed for general information about the donor but not their identification. This was one of the reasons why the law was challenged, which led to an intermediate solution being adopted of allowing research but not granting it legal effects.

An important aspect that must be taken into account is that both Law 35/1988 and Law 42/1988 regulated issues referring to life prospects. The first one defined the concepts of "pre-embryo", "embryo" and "foetus". Given that birth determines legal status, we must point out that the embryo does not possess rights, since these are only possessed by persons. Embryos are legally protected assets, but they cannot be considered to be persons or individuals. For this reason, they do not possess fundamental rights. The doctrine of the Constitutional Court restricts the protection of the legal system to persons, hence life is a fundamental right related to birth.

Moreover, for the law to protect the embryo it must be alive, developing, and this prompts especially relevant questions: must surplus embryos, created in vitro, be destroyed? Can they be used in experiments? If they are conserved, until when? If there are defects can they be genetically modified and reimplanted? The law permitted manipulations for diagnostic and therapeutic purposes only: any intervention in the embryo or the foetus must be for the purposes of its wellbeing.

A complex question is the distinction between viable and unviable embryos, a distinction established many years ago by law with respect to the

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[4] Until the Constitution of 1978 was passed, investigation of paternity was prohibited in the Spanish Civil Code in the interests of a paternalistic and traditional idea of the family unit.

person. The law of 1988 established that research could be carried out with unviable embryos (those that, if they were transferred to a woman, would not lead to a viable pregnancy); and that viable embryos, but not transferred, could be frozen for a maximum period of five years. However, the law did not establish what would happen after that time, thus generating a great deal of doubt and hesitation. While some argued that they should be able to do research with these (viable) embryos, others considered that they could only be transferred to women (whether or not they were the owners of the said embryos).

Moreover, one must remember that the two laws of 1988 were each the subject of a non-constitutionality appeal by a group of Partido Popular MPs. Among other arguments, they said that the Law of Assisted Reproduction affected the structure of the family and the development of the child's personality, as it allowed women to be able to use assisted reproduction techniques without having a male partner.[5] The Constitutional Court rejected this appeal in 1999, basing itself on the famous sentence of 1985 that declared abortion to be constitutional.[6] Furthermore, the court upheld in its reasoning that the Constitution does not regulate one single type of family, opening up the range of possibilities to single-parent families and to the irrelevance of the sexual variable (the declaration of same-sex marriage as constitutional, almost 20 years later, consolidated precisely this line of argument).[7]

As the Constitutional Court rejected the appeals, in 2003 the Partido Popular reformed the 1988 Law of Assisted Reproduction (which had been passed by the Socialists). The reform was particularly conservative, as it hindered both the possibility of researching with pre-embryos, and in vitro fertilization. It prevented more than three pre-embryos in each cycle from being created, which moreover could only be used for procreation purposes, and not research. With this, if the attempt to get pregnant failed, the whole process would have to be repeated, with the cost, in terms of health and finances, that this represented

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[5] "The same incongruence can be ascribed to other passages of the law: while the exposition of reasons refers to the 'human couple' — which would per se disregard the constitutional protection of marriage — article 6 refers to the 'single woman', or any woman; the allusion to the fundamental rights and freedoms in the exposition of reasons would merely be an obvious example of the perversion of the language which subverts the system and supposes an arbitrariness by the legislator, which the Court is called upon to put a stop to. The object, in principle praiseworthy, of the law would eventually lead to a substantial alteration of the concept of the family and the rights of children; by making conception by single women possible, keeping the father — the donor — anonymous." Constitutional Court (Plenary), Sentence no. 116/1999 of 17 June; RTC 1999\116.

[6] Sentence no. 53/1985, of 11 April, of the Constitutional Court, RTC 1985\53.

[7] Constitutional Court (Plenary), Sentence no. 116/1999 of 17 June; RTC 1999\116; and 12/1996. Both sentences outline and improve ST 53/1985 mentioned in the previous note.

for women. The ultimate aim of this reform was to adapt artificial reproduction to Catholic doctrine, ensuring that there would be no motherless pre-embryos.

In 2006, with the Socialists back in power, this issue was reformed once again through Law 14/2006, of 26 May, on Human Assisted Reproduction Techniques. The most novel thing about this law, still in force, is that it allowed for the creation of pre-embryos that were necessary to ensure reproduction, that is, that more than three pre-embryos could be created (although they could only be transferred to the woman three at a time, to avoid multiple births). Given that in this way surplus embryos were generated, the law allowed them to be used in research, destroyed, or frozen for use in procreation later.

This law establishes that in order to undergo this treatment there must be "reasonable possibilities of success". This is a euphemistic way of referring to the age of the prospective mother, a reference that is completed with article 6.2 of the Law of Assisted Reproduction, which requires the woman to be informed of the risks for the offspring "that may result from maternity at a clinically inappropriate age". The problem of "grandmother-mothers", women at an advanced age who can, based on these techniques, get pregnant, is not clearly dealt with in the law.

Lastly, reproductive cloning is prohibited, thus indirectly permitting therapeutic cloning, very useful for research (for example, for the obtainment of embryonic stem cells).[8]

3. SOCIAL ASPECTS OF ASSISTED REPRODUCTION

At the present time the debate about certain issues involved in the use of these techniques is ongoing, since increasingly widespread access to human assisted reproduction techniques requires an analysis that takes into account the financial aspects and the repercussions with regard to access to biological resources in the health system. The French National Ethics Committee, always a point of reference in these issues, has repeatedly and clearly pointed out that very profound changes are taking place in the way of conceiving a child (and in

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[8] Thus, article 36.2 of the Law of Biomedical Research establishes that "2. The use of any technique for obtaining human stem cells is permitted, for therapeutic purposes or for research, which does not entail the creation of a pre-embryo or of an embryo exclusively for this purpose, in the terms defined in this law, including the activation of oocytes through nuclear transfer".

what it means to be parents), as forms of procreation are evolving quickly and the technological limits are shifting to extremes that until recently were unthinkable.[9] It is therefore necessary to pay very close attention to the ethical aspects and to try to construct an informed social debate to permit decision making on legal policy in keeping with the feelings of society.

Furthermore, it may be said that society's attitude to assisted reproduction is currently one of widespread acceptance, although this is set against a backdrop of moral and religious ideas opposed to it. It is interesting to point out that in its doctrine, the Catholic Church is opposed to it, but in practice it does not insist on its prohibition — unlike in other issues, abortion especially. The other major religions, Orthodox, Judaism and Islam, are not in favour of the use of assisted reproduction techniques either; the minority Reformed Churches are rather more permissive.

From radically different positions, the consideration of respect for women's rights means that feminist analyses are not in favour of these techniques either. The belief that in certain cases women are put under pressure, that the information is not as explicit as it ought to be with regard to the highly intrusive nature of the procedures (egg donation, for example), and the idea that informed consent is neither so informed nor so free in some cases, leads them to wonder whether there might be some obscure areas behind the undoubted advantages that should be made clear and debated together.

It is clear that the same traditionally patriarchal approaches underpin the new technologies. What is presented as an achievement for women has important costs that must be taken into account, since once the process has begun control over it is completely out of their hands, and what is considered to be a new reproductive option could turn into a new form of oppression. The existence of other alternative choices must be made clear, such as adoption; it must be remembered that success rates are low, in some assisted reproduction techniques especially; and if they fail, having to accept sterility over and again — and definitively — generates further suffering.

Society must decide if the right to life also implies the acknowledgement of the right to create life, and what the reach and limits of reproductive rights are. Does the right to have children at all costs exist? Although this question refers not only to the financial aspect, we should not lose sight of the fact that the distribution of resources is a problem of the first order with regard to

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[9] Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé, *Avis* 126, de 2017 *sur les demandes sociétales de recours a l'assistance médicale a la procréation*. www.ccne-ethique.fr/fr/publications/avis-du-ccne-du-15-juin-2017-sur-les-demandes-societales-de-recours-lassistance.

health. Healthcare budgets are necessarily limited and the costs of health increase in step with the standard of living and the possibilities of the technique. This implies that costs must be limited, which means choosing priorities in the population's healthcare. Services and their financing must be placed in order of importance according to the priorities of the population to which public health programmes are addressed. We shall now refer to the principal points that are currently being debated.

3.1. Sex selection

Every cell in the human body contains a double set of chromosomes, except for eggs and sperms, which only have one set. Since assisted reproduction makes it possible to isolate sperms, it is possible to know if they carry a Y or an X chromosome, in other words, if they will give rise to a male or a female. This information makes it possible to choose the sex of one's children, which could have great repercussions in biomedicine.

Natural selection has evened out the birth of boys and girls, although the proportion is not exactly 50%, which allows us to deduce that the alteration of this proportion on a large scale could have repercussions for the survival of our species. For this reason, we wonder whether we should replace the randomness inherent in pregnancy with a conscious and deliberate choice of one sex or the other; and, in this case, what requirements should be met. We must take into account that socio-political factors have historically favoured one of the sexes. For example, in China, a collateral effect of the one-child policy was that in just a few decades the male population exceeded the female. The reason for this is that, in an eminently agricultural economy where physical strength is important, parents resorted to killing baby girls to ensure that the only legally permitted child would be a boy. Studying this issue in detail, Amartya Sen, the winner of the Nobel Prize for Economics in 1998, demonstrated with figures that there were more than one hundred million fewer women in southeast Asia,[10] the consequence of the policies of exclusion in both education and healthcare. These precedents explain the precaution with which the idea that couples should be allowed to choose their children's sex is approached.

There is on the other hand no justification for preventing sex selection in specific cases (family balance, for example; a couple who, hoping for a girl, are

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[10] Sen, A. (1995). *Nueva Economía del bienestar. Escritos seleccionados.* University of Valencia, p. 361.

going to have their fourth boy) and/or in socio-political contexts where the ratio of men to women remains stable. Indeed, if assisted reproduction allows for countless choices related to parenthood, how does one justify that children's sex cannot be chosen too? From this perspective, it is considered that the prohibition on choosing the sex of one's children is an unjustified taboo and that, even from the point of view of the social situation in the countries we have mentioned, pre-implantation selection is better than subsequent female infanticide. It would be enough, therefore, to impose reasonable requirements so that parents may exercise this option (for example, having more than one child of the same sex).

Notwithstanding that, article 26.c.10 of the Spanish Law of Assisted Reproduction regards sex selection that is not for therapeutic ends, or for unauthorized therapeutic ends, as a very serious infringement, and stipulates fines of up to one million euros. In other words, selection is only permitted in the event of the existence of hereditary diseases linked to the X or Y chromosome.[11] It is a very widespread prohibition, established also in article 14 of the European Convention on Bioethics. However, an important fact is that sex selection is not punishable in criminal law. Articles 159 and 160 of the Criminal Code penalize the fertilization of eggs for purposes other than procreation, reproductive cloning, procedures directed at race selection and altering the genotype other than for therapeutic reasons, but not sex selection, whereby we may infer that society does not disapprove of it as strongly as it does other practices associated with assisted reproduction or genetic manipulation.[12]

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[11] In a court in Mataró a 45-year-old woman, the mother of five male children, requested that sex selection be accepted in order to conceive a female. The judge issued a favourable ruling on 2 August 1990, against which the prosecutor, who had already issued an unfavourable report, appealed. The Audiencia de Barcelona revoked the ruling of the court in Mataró on 12 November 1990, and in the higher court's ruling it stated that it is "the mother for the child and not the child for the mother". On the contrary, in favour of sex selection, see Eguzcue (1993). "Sex Selection: Why Not?". *Human Reproduction,* vol. 8, no. 11, p. 1777.

[12] The objective of the first preimplantation genetic diagnosis was precisely to ascertain the sex of the embryo in certain families that were known to be carriers of gender-linked diseases (Alan Handyside, 1990). The question is whether there may be more causes, besides medical ones, that justify sex selection. In February 2003, the Bioethics and Law Observatory published a *Document on Sex Selection* which urged the public authorities to legalize sex selection by parents. Some of the recommendations were the following: "2. Although it is not possible to speak of the existence of a right to choose the sex of one's future children, we consider it unreasonable for the state to prohibit it — as is currently the case — and that it should be authorized if reliable techniques exist and if the means employed for it are proportional to the end it is desired to achieve: 3. Sex selection through the selection of spermatozoids for the reason of satisfying the preferences of the parents, should be authorized". CASA-

Sex selection — its rejection for non-therapeutic reasons — has in fact been the only case that has given rise to the intervention of the courts in Spain.

Lastly, sex selection confronts us with the alternative that places making decisions according to strictly individual criteria in opposition to resolving matters in accordance with the collective interest. From legal and ethical, medical and sociological points of view, the free selection of the sex of one's children generates problems that may be resolved differently if one considers it to be simply an individual decision, or as something that has repercussions in the community. This leads us to the fundamental dilemma between the individual's rights and those of the group: to what extent can an individual be asked to renounce their best interests on behalf of a generic group?

The very idea of the world and society will be decisive when identifying the interests at stake and establishing what values should be protected and their order of importance. The conclusions reached must be compared with those of society as a whole in a free and informed discussion. The existence of a particular law does not definitively settle the issue: laws and society are mutually interrelated and the evolution and the life of both are largely derived from this influence.

3.2. Oocyte donation

Oocyte donation poses specific problems, including the debate about whether simple compensation should be established or there should be a payment for donation. Bearing in mind that the oocyte donor has to undergo a treatment not without its risks and make a number of journeys to the clinic, compensation is considered acceptable. In Spain, the amount of compensation paid must follow homogeneous criteria and be set by the government, as proposed by the scientific companies involved and the assisted reproduction clinics.

Nevertheless there is fierce debate, since although the gratuity rule in donation is still in force, in a context of the commercialization of interpersonal relationships and of the trafficking of the human body, the discussion about whether compensation is actually that or a concealed payment is a very relevant one, even more so when the economic crisis allows financial incentive to "buy the willingness" to do what is praised as caring and altruistic. It is known

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DO, M. (coord.). *Document on Sex Selection*. Bioethics and Law Observatory, February 2003, at http:// hdl.handle.net/2445/11371.

that given the differences between average and low salaries in neighbouring countries, what for some is compensation may for others clearly be regarded as payment. This has given rise to several cases of so-called donor tourism — yet another form of reproductive tourism that takes place in a globalized world due to the differences in the law and spending power between countries.

In 2001 the Bioethics and Law Observatory published a *Document on Oocyte Donation* in which,[13] among other considerations, it made the following recommendations: *a*) be especially rigorous with the information supplied to potential donors, information that should describe the risks, both present and future, in as much detail as possible; *b*) a civil liability insurance policy should be created, thus avoiding the consequences of the hypothetical contingencies falling on the healthcare personnel or the public administrations; *c*) the authorities should set a level of compensation according to fair and uniform criteria, bearing in mind both the potential dangers to which donors are exposed and the opinion of the scientific companies involved and the assisted reproduction clinics; and lastly, *d*) the campaigns used to capture possible donors should not be advertisements to encourage it, but they should provide serious thorough information.

3.3. Cryopreservation of oocytes by young women

The other side of the coin of this technology is that, due to the demands of their job, many women freeze their eggs for when they may hopefully enjoy job stability; they are sometimes prompted to do so by the company they work for, as has happened with Apple and Facebook. This, which may be seen as an achievement, also has its downside, since it shows us how assisted reproduction techniques can be used to perpetuate or mask job insecurity, especially women's.

In France, for example, this practice is prohibited if it is not for therapeutic purposes (before chemo- or radiotherapy treatment, for example), but cryopreservation is increasingly widespread as a precaution with a view to a possible late pregnancy due to having to postpone maternity for work reasons. Given that the hormonal stimulation and egg extraction procedures are not innocuous, we consider that society must reconsider the social model that forces women to suffer this tremendous age imbalance between getting preg-

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[13] *Document on Oocyte Donation*, at http://hdl.handle.net/2445/11372.

nant and working. What is more, with this a new market is generated that, for reasons of proportionality, medical expenses, the lack of guarantees in the results and even the need to ask for them, is hard to defend.[14]

3.4. Donor anonymity

Spain is one of the countries where most in vitro fertilizations are performed, due, among other things, to the fact that its legislation ensures egg donors' anonymity. Indeed, the general rule is, in principle, anonymity, although the law establishes two important exceptions: *a*) a minor or her representatives may obtain general information about the nature of the donor. This right is also enjoyed by the woman receiving gametes or pre-embryos; *b*) in the event of danger to the woman's life and health, or if it is essential in criminal proceedings, the clinic must reveal the donor's identity. Even so, the information does not imply publicity about donors; it can only be used to avoid danger or to achieve the proposed legal end, and it does not generate reciprocal rights or responsibilities (maintenance payments, inheritance, etc.).

Donor anonymity is currently a controversial subject and there seems to be a tendency to lift anonymity. Several countries have reversed it and have seen donations fall drastically; for this reason, clinics are opposed to it and justify the permanence of the current legislation.

The fact is that anonymity goes against the increasingly widespread tendency to acknowledge the existence of the so-called right to know one's origins (which is not disputed in the case of adoption, for example). This right of the child to know their biological origins leads ultimately to the disclosure of the identity of the person who supplied the genetic material, even when it is not necessary for health reasons, simply because it is a right in itself.

In this respect, the Bioethics Committee of Catalonia has recently issued a ruling on this matter in which, still with some reluctance, it advocates for it to be possible to know donors' identity. Specifically, conclusion number 12 reads as follows:

> The consequences that may result from the suppression of anonymity in the case of gamete donation cannot be reasons for the state depriving the person conceived with gametes from a donor of an important aspect of their life: the free-

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[14] On this point see the abovementioned *Avis* 126, of the French CCNE, 2017.

> dom to choose what significance they attach to the genetic components of their identity.[15]

In fact it depends on how article 7 of the Convention on the Rights of the Child is interpreted, adopted by the United Nations General Assembly on 20 November 1989 and ratified by Spain on 26 January 1990, in which it establishes that children have the right, as far as is possible, to know their parents and be cared for by them.

Although we shall analyse it in greater detail in the next section, we must point out that the Portuguese Constitutional Court has declared the law permitting surrogate motherhood and the anonymity of oocyte donors to be unconstitutional.[16] The sentence maintains that children's right to know who their parents are in a genetic sense (egg and sperm donors) prevails over the latters' legal right to anonymity up to now. Some have interpreted that this part of the sentence is a form of boycotting not surrogate motherhood but assisted reproduction techniques (this same court, although with a different composition, had years earlier ruled in favour of anonymity), as it will reduce the already scant donations even further. We must add that this is the first time that egg donors' right to anonymity has been declared unconstitutional, something that sooner or later could affect the rest of the continent.

Lastly, the advances in biocomputing and the creation of huge genetic databases are making anonymity a thing of the past, since it is increasingly easy, both technically and financially, to take a sample from a person and locate their genetic parents.

3.5. Saviour siblings

In vitro reproduction techniques make it possible to create several embryos, the reason why their usefulness transcends the objective of reproduction, going as far as those typical of biomedicine. Indeed, when choosing which embryos are transferred to a woman (legally no more than three), the ones are chosen that a priori seem to be in the best state to ensure a viable pregnancy. That is, three pre-embryos are chosen from the group created, and the selection criterion is not chance, but the greatest viability to ensure pregnancy.

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[15] Terribas Sala, N.; Farnós Amorós, E. (coords.) (2016). *El derecho a conocer los orígenes biológicos y genéticos de la persona*. Bioethics Committee of Catalonia.

[16] Constitutional Court. Sentence 225/18, May 2018.

However, this selection may be made not just from the point of view of achieving pregnancy, but also with the aim of avoiding the development of chromosomal or genetic anomalies, some of which may be hereditary. This is what pre-implantation genetic diagnosis is for, to ensure that not only does the transferred pre-embryo have more possibilities of development, but also that it is free of potential anomalies that may result in illnesses in the near future.

In the case we are now looking at, prenatal diagnosis is used to select pre-embryos that not only meet the above requirements (viability for the pregnancy, absence of certain chromosomal or genetic anomalies) but which in addition are histologically compatible with other siblings already born but which are sick. The usefulness of the saviour sibling for a brother or sister (it could also be used to help its parents) lies in the possibility of obtaining hematopoietic (blood) stem cells from the umbilical cord, or in the possible performance of a bone marrow transplant.

In fact the search for siblings whose blood might be compatible with a sick child is not new, but in the past it was carried out using random methods (for example, engendering a child by natural methods in the hope of it being compatible and, if it were not, trying again and again, without any legal limits). This explains why the debate on this subject did not begin in earnest until the year 2000,[17] when pre-embryos were selected for the first time with the aim of saving or helping a child already born.

The Law of Assisted Reproduction of 2006 legalized this kind of medical action, justifying its moral legitimacy in the preamble:

> Pre-implantation genetic diagnosis opens up new pathways in the prevention of genetic diseases for which treatment is presently lacking, and to the possibility of selecting pre-embryos so that, in certain cases and under the proper administrative control and authorization, they may help to save the life of the sick relative.

The term saviour sibling, besides not being very scientific, is in fact pejorative and has been created by people opposed not to the selection of pre-embryos but to any progress in biomedicine that is contrary to the doctrine of the Catholic Church.[18]

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[17] Pinto Palacios, F.; Marcos del Cano, A. (2016). "'Bebé medicamento', protección de la salud y sistema sanitario público: una reflexión desde el principio de justicia". *Universitas*, no. 24, pp. 243-265.

[18] The comparison between moral and religious ideas is also worth bearing in mind. Thus, the reproaches aimed at the family that had the first saviour sibling were answered in the following way:

The prohibition of this kind of medical intervention is part of a narrative that also justifies the prohibition of in vitro fertilization, divorce and contraception, with the underlying danger, always present in this kind of imposition, of a slippery slope that ends in a political theocracy where any kind of thinking at odds with the clergy is pursued (the American Protestant neocons include the spreading of creationism in schools in the narrative package).

Indeed, behind the moralistic appearance of expressions such as instrumentalization of life, a violation of the Kantian mandate (treat every individual as an end in him or herself, and not merely as an instrument), or the listing of the countless psychological calamities that await the pre-embryo thus selected, there lies hidden a monolithic and fundamentalist narrative that wants the entire population to be governed solely and exclusively by axioms based on blind and unthinking faith. There are many Catholics who use the latest reproductive techniques, which shows once again that the problem does not lie in the beliefs but in those who try to impose theirs and use apparently scientific arguments to universalize theological statements. As the title of the excellent study by Fernando Pinto stresses, saviour siblings are "born to save", and that is the perspective from which we must examine this issue.[19]

3.6. Surrogate motherhood

Few issues arouse more debates in bioethics than the question of surrogate motherhood, hence there is not even any agreement over what to call it. Thus, we can find a range of expressions that oscillate between the pejorative (for example "wombs for rent") and the euphemistic ("gestation by substitution"), with achromatic shades such as the heading of this section.

Basically, through this practice a woman engenders a child that has been ordered by another or others, and then hands it over, either paid for or free of charge, to those persons (called clients). The gestation may be the result of completely alien genetic material or with her own eggs, a matter that has important repercussions as far as the facility of the procedure to achieve pregnancy and the connection of the intended parents with the future child are concerned.

"They claimed that their decision sought to preserve the good of the family and that, in accordance with Jewish law, they were obliged to use all the means at their disposal to preserve Molly's life." Ibid.

[19] Pinto Palacios, F. (2015). *Nacidos para salvar. Un análisis ético-jurídico del "bebé medicamento"*. UNED.

The embryo may contain genetic material of the gestating mother (she provides the egg) or not (the egg or the embryo is donated by a third party); the embryo may contain genetic material of the man and the woman who order the surrogate motherhood (they supply the egg and the sperm); it may contain genetic material of just one of the two (for instance in the case of same-sex couples); or even of neither of them (as in the case of the donation or even the purchase of this material).[20]

In an extreme situation, up to five people could take part in the surrogate motherhood: the gestating mother, the couple who eventually take the child, and a man and a woman who supply the sperms and oocytes but who are unconnected with the previous ones. And if on top of that there is donation of mitochondrial DNA, we could include a sixth person.

There are additionally many intermediate problems: the possibility of abortion, the possibility of the baby being born with health issues, of the fault lying with the gestating mother for not looking after herself; or with the egg donors due to genetic problems, with the hospital, or a third party, or chance; that the gestating mother wants to keep the baby and break the contract, that it is the contracting parties who decide not to continue with it once pregnancy has begun, that there is a multiple pregnancy and they have not agreed on what to do with the surplus embryos. Other aspects that have to be taken into account are the rights of the child to know who its biological parents are; the legal problems derived from the fact that fertilization takes place in one country, the contract is signed in another, the birth takes place in a third country and the handover in a fourth, or contractual problems arising from the participation of third parties (oocyte donors, intermediaries, etc.), among other things.

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[20] In a sentence of the European Court of Human Rights, Italy was condemned because it withdrew parental authority from a couple over a minor who had been conceived in Russia through a company in the surrogate motherhood business (in Russia it is legal). It was discussed whether for surrogate motherhood to be legal, the genetic material had to be from at least one of the contracting parties. In Russia this question is not regulated, but it was deduced that the genetic material could be donated by third parties without this preventing it from being a surrogate motherhood (the argument of the Russian lawyer of an intermediary company was really ingenious: the fact that the couple have to provide genetic material does not mean that it actually has to be theirs, as there is nothing to stop them from buying it in an egg bank and, then, yes, supplying it...); and from the court's sentence, condemnatory for Italy, it must also be inferred that it is not necessary for the genetic material to be from one of the contracting parties for it to be considered a legal case of surrogate motherhood. Moreover, the Court considered that checking whether the father was the biological father or not was an interference proscribed by article 8 of the European Convention on Human Rights. European Court of Human Rights (section 2). Paradiso and Campanelli v. Italy. Sentence of 27 January 2015. A similar problem justified the condemnation of France in Mennesson v. France. Sentence of 26 June 2014. European Court of Human Rights. JUR 2014/176908.

The French National Ethics Committee, mentioned above, has repeatedly shown itself to be opposed to the practice and has insisted on the dangers for the gestating mother and the instrumentalization and commercialization of the people involved; it also refutes legitimization based on an idea of autonomy that entails a "*mutation anthropologique majeure*" and the de facto prioritization of the clients' interests.[21]

To understand the position of Spanish legislation, which, as we have said, declares these types of contracts null and void,[22] we have to distinguish three paradigms.

The first would advocate the possibility of a woman offering herself as a gestating mother for a price.[23] It would be a neoliberal model in which someone offers their body like any other good or service. It would be based on the contractual freedom typical of a pure capitalist system. Who best describes this paradigm is a lawyers' association with 400,000 members:

> The American Bar Association observes that, "it is undeniable that the hiring of services for gestating children by substitution in return for money represents a market". It praises this "market" and it observes that, "market-based mechanisms have made the efficient functioning of gestation by substitution possible internationally". The American Bar Association rejects that the rule of the child's higher interest be applied to gestation by substitution, it rejects most of the forms of examining suitability and assessing the competence of the aspiring parents, it rejects that limits be imposed on the payments made to surrogate mothers and gamete donors, it rejects that requirements for the issuing of licenses be imposed on gestation by substitution agencies, it rejects the rights to birth certificates or to information about personal origins, it rejects the Hague Convention on the Protection of Children and Cooperation in Respect of Intercountry Adoption (1993) […]. The American Bar Association claims that, "any and all efforts that are addressed to regulating the international gestation by substitution market in itself are on the wrong track". In fact, it advocates that all international instru-

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[21] See *Avis* 110 of 2010, *Problèmes éthiques soulevés par la gestation pour autrui*, and the abovementioned *Avis* 126 of 2017 of the CNNE, at www.ccne-ethique.fr/fr/publications/problemes-ethiques-souleves-par-la-gestation-pour-autrui-gpa.

[22] The Supreme Court recalled in a sentence that this solution is in keeping with that recommended in the report of the Ad Hoc Committee of Experts on the Progress of Biomedical Sciences, CAHBI, of the Council of Europe. Supreme Court. Civil Court. Sentence no. 835/2013, of 6 February. RJ, 2014/833.

[23] On this point, see Lamm, E. (2018). "Gestación por sustitución y género: repensando el feminismo." In: García Manrique, R. (coord.). *El cuerpo diseminado. Estatuto, uso y disposición de los biomateriales humanos*. Aranzadi.

> ments in matters of gestation by substitution should dispense with the human rights dimension; hence it rejects the "regulation of the gestation by substitution industry for the purposes of reducing human rights violations".[24]

The nightmare scenario that we can imagine is the creation of farms of women in developing countries so that couples from industrialized countries can go there to look for a mother for their babies, that is, the exploitation on an industrial scale, through bioethical tourism, of surrogate motherhood. Besides, what difference is there between selling a child and surrogate motherhood at a price? In California, where these kinds of practices are permitted, it is considered child selling if the contract is signed during pregnancy (or after birth), but it is not child selling if it is signed before pregnancy. The distinction could not be more arbitrary: what if it is signed between the creation of the embryo and its transfer to the woman? Can it be signed after transfer, but before it attaches to the uterus? Can it be signed retroactively?

This is the paradigm that the Spanish Supreme Court categorically rejects:

> But along with it, in our legal system and in that of the majority of countries with legal systems based on similar principles and values, it is not accepted that the spread of adoption, even international, and the advances in human assisted reproduction techniques may infringe the dignity of the gestating woman and the child, commercializing gestation and filiation, objectifying the pregnant woman and the child, allowing certain intermediaries to profit from them, making possible the exploitation of the state of need in which poverty-stricken young women find themselves and creating a sort of selective citizenry in which only those who have high financial resources can establish parent-child relationships that are out of reach for the majority of the population.[25]

The second paradigm would advocate the same possibility, but without a price, that is, for free. Only the expenses generated by the operation would be paid (health care, postnatal care, etc.). The criticism that is usually made in this case is that a concealed market would be generated, as it is difficult to understand why a woman would undergo a pregnancy of this kind if she has

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[24] United Nations Organization, Special Rapporteur's report on the sale and sexual exploitation of children, including child prostitution, the use of children in pornography and other material that shows the sexual abuse of children. Council of Human Rights. 37 period of sessions. 26 February to 23 March 2018.

[25] Supreme Court. Civil section. Sentence no. 835/2013, of 6 February. RJ, 2014/833.

no previous dealings with the potential parents. However, this was the model proposed in 1989 by the Council of Europe's Committee of Experts on Progress in the Biomedical Sciences (CAHBI), the predecessor of the Steering Committee on Bioethics, when it recommended that:

1) No doctor or establishment shall use artificial procreation techniques for the conception of a baby that will be carried by a surrogate mother.
2) No contract or agreement between a surrogate mother and the person or couple on whose account she carries the baby may be invoked.
3) All intermediation between the people involved in a surrogate maternity must be prohibited, as well as all forms of related advertising.
4) Nevertheless, in exceptional cases established by national legislation, countries shall be able to envisage, without making an exception to section 2 of this Principle, that a doctor or an establishment may proceed to fertilize a surrogate mother using artificial procreation techniques, on condition: *a*) that the surrogate mother shall not profit in any way from the operation; and *b*) that the surrogate mother may, after the birth, choose to look after the baby.

This model, with qualifications, is the one put forward as a proposal in the Bioethics and Law Observatory.[26] Basically, this institution's view is that surrogate motherhood should be prohibited as a general rule because it constitutes a form of objectification and commercialization of women. However, if (even knowing that numerous international organizations have ruled in this same way, that regulations to legitimize *faits accomplis* should not be established, and that in comparative law the regulations are diverse) the state decides to regulate this practice, it would be necessary to establish requisites that offer minimal guarantees.

These requisites would be that: *a*) there is no fee; *b*) the gestating mother has a direct link with whoever finally takes charge of the child; *c*) that the genetic material should be from at least one of the contracting parties, *d*) that it is not the gestating mother's first pregnancy; *e*) that a judge should intervene in a voluntary jurisdiction file, both before the contract is signed, to avoid abuses, and after the birth, with the aim of guaranteeing the woman's right to change her mind.

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[26] On this point read Navarro Michel, M. (2018). "La gestación por sustitución, ¿debe ser regulada? Y, en su caso, ¿cómo?" In: García Manrique, R. (coord.) *El cuerpo diseminado. Estatuto, uso y disposición de los biomateriales humanos*. Aranzadi.

The third model would be the Spanish one.[27] The contract is null and void, whereby the person gestating is the mother to all intents and purposes. There is no specific penalty for this kind of contract, which does not preclude it being a crime if it is considered that an illegal adoption has taken place.[28] The problem in our case is that, in today's world, there is nothing to stop someone going to countries where this kind of contract is legal and returning to Spain with the baby.[29] Some rather uncomfortable case law has been produced with this issue.

If the couple come back from another country with a certificate that establishes them as the baby's legal parents, there are three possibilities: *a*) if it is a man and a woman, no questions are asked, whereby it is presumed that the baby has been gestated by the mother and the certificate is regarded as valid; *b*) if it is two women, no questions are asked either, presuming that one of the two is the biological mother; but *c*) if it is two men, there is no option but to ask.

This third case is the one that ended in the Spanish courts. Indeed, due to the attempt by the Registry Office to enter two men as parents in consideration of the "priority interest of the minor", the courts found against the couple. The argument of the court in Valencia to refuse registration and to question the validity of the certificate they provided was that "in the current state of science, [men cannot] conceive or engender."[30]

In fact, there is an underlying symbolic question with regard to this case. As the minor's interest prevails, in practice he or she has all the rights despite coming from a surrogate mother from another country. And in the case of two

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[27] On feminism and support for the prohibition of surrogate motherhood, it is interesting to read Palop, M. E. (2018). "Argumentos contra la gestación por sustitución." In: García Manrique, E. R. (coord.) *El cuerpo diseminado. Estatuto, uso y disposición de los biomateriales humanos*. Aranzadi.

[28] Thus, article 221 of the Criminal Code establishes that:

> 1. Those who, in return for financial gain, hand over to another person a child, their own or any minor even though there is no tie of filiation or kinship, avoiding the legal procedures of guardianship, fostering or adoption, for the purpose of establishing a relationship analogous to that of filiation, will be punished with prison sentences of one to five years and will be disqualified especially from exercising the right to parental authority, tutelage or guardianship for a period of four to ten years.
>
> 2. The person who receives the child and the intermediary will be punished with the same sentence, even if the minor was handed over in a foreign country.

[29] The analysis made by Encarna Roca, a Supreme Court magistrate, in her 2015 paper entitled "Dura lex sed lex. O de cómo integrar el interés del menor y la prohibición de la maternidad subrogada" is interesting. *Boletín del Ministerio de Justicia,* June, pp. 301-338.

[30] Sentence no. 193/2010, of 15 September, Court of First Instance Number Fifteen of Valencia, AC 2010\1707.

men, there is nothing to prevent one of them from being named as the father and the other as the hypothetical adopter. In fact, this was the solution offered by the Spanish Supreme Court, adoption or fostering, in the case we are discussing.[31] It was just that the couple wanted both of them to appear as parents (they had been to California, where this kind of contract is legal, and they returned from the USA with a certificate to prove that they were the contractually legitimate progenitors) and for this reason registration was refused.

The truth is that it is difficult to get it right in an issue that is beginning to move billions of dollars/euros, with middlemen, agencies, tax revenue, and so on, in a context of huge social, political, economic and legal inequalities, and with the underlying problem of children who are already here with us and who must be legally protected. As the dissenting opinion in the Supreme Court sentence, cited above about the baby from California, argued (it voted against granting validity to the Californian surrogate motherhood by five to four):

> This statement cannot be generalized […] besides: *a*) it is a manifestation of the right to procreate, especially important, for those who cannot have genetic children of their own, as in this case; *b*) the gestating mother's power of consent cannot simply be underestimated; *c*) the mother's consent is given before the legal authority that ensures it is given freely and in full knowledge of the consequences; and *d*) as it is a free and voluntary agreement she is hardly being objectified or exploited against her freedom and autonomy and under no circumstances does it affect the interests of the minor that is born into a family that loves it. It is the child who is given a family, and not the family that is given a child, and it is up to the state to offer a legal framework that protects it and provides it with the necessary legal certainty.[32]

As we said earlier, Portugal, which was one of the few European countries where this practice was legalized, has just looked on with astonishment as the Constitutional Court has declared this law unconstitutional.[33] The sentence

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[31] Supreme Court. Civil Section. Sentence no. 835/2013, of 6 February. RJ, 2014/833.

[32] In another part of the dissenting opinion the following is stated: "[...] it is obvious that when presented with a fait accompli such as the existence of minors in a family that acts socially as such and which has acted legally in accordance with foreign law, applying the domestic regulation as a question of public order harms the children, who could find themselves in situations of neglect, like the one in the Italian case, and they are deprived of their identity and family nucleus in contravention of international law, which requires consideration of the interests of the minor, an identity that prevails over other considerations, as was pointed out by the Court of Justice of the European Union". Supreme Court. Civil Section. Sentence no. 835/2013, of 6 February. RJ, 2014/833.

[33] Constitutional Court. Sentence 225/18, May 2018.

will not be applied retroactively, as it would cause absolute turmoil in the couples who have made use of this possibility, but it has important symbolic consequences for all other Western countries.

Lastly, the UNO has issued a stern statement against this practice, which it generally equates with child trafficking. However, it urges countries to take steps to regulate it.[34]

To sum up, the alternatives are: *a*) prohibiting this institution completely and absolutely to avoid the objectification and commercialization of women, and *b*) regulating as far as possible a practice that is already unstoppable in the world. In this second case, if it is regulated, it must be considered whether it is done free of charge or whether surrogate motherhood becomes just another product or service on the market, where the price is set by supply and demand.

4. Recommended reading

Cambrón Infante, A. (2011). *Reproducción asistida: promesas, normas y realidad*. Madrid: Trotta.

Carro Fernández, S.; González Tascón, M. (2013). *Salud reproductiva, legislación y opciones de maternida*. Oviedo: Trabe.

Casado, M; Egozcue (coord.) (2011). *Documentos sobre donación de ovocitos.* Observatorio de Bioética y Derecho.

Comité Consultatif National d'Éthique (2010). *Problèmes éthiques soulevés par la gestation pour autrui.* Available at: www.ccne-ethique.fr/fr/publications/problemes-ethiques-souleves-par-la-gestation-pour-autrui-gpa.

— (2017). *Avis du CCNE sur les demandes sociétales de recours à l'assistance médicale à la procréation (AMP).* Available at www.ccne-ethique.fr/fr/publications/avisdu-ccne-du-15-juin-2017-sur-les-demandes-societales-de-recours-lassistance.

Florencia, L. (2014). "Las paradojas de la reproducción asistida y el género. Dejando de lado fotografías anacrónicas." *Género y bioética*, Casado, María; Luna, Florencia and Vázquez, Rodolfo, eds. Mexico City: Fontamara y Suprema Corte de Justicia de la Nación, pp.73-93.

— (2018). "From the Middle Ages to the 21st Century. Abortion, Assisted Reproduction Technologies and LGBT Rights in Argentina." *Canadian Journal of Bioethics*, 1(2), pp. 26-36.

García Manrique, R. (coord.) (2018). *El cuerpo diseminado. Estatuto, uso y disposición de los biomateriales humanos*. Cizur Menor: Aranzadi.

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[34] United Nations Organization, *op. cit.*

García Moyano, L.; Pellicer García, B.; Buil Tricas, B.; Juárez Vela, R.; Guerrero Portillo, S.; Antón Solanas, I. (2016). "Análisis bioético de la generación de 'bebés medicamento'." *Revista Bioética y Derecho*, no. 36, pp. 55-65.

Lamm, E. (2018). "Gestación por sustitución y género: repensando el feminismo." In: García Manrique (coord.). *El cuerpo diseminado. Estatuto, uso y disposición de los biomateriales humanos*. Cizur Menor: Aranzadi.

Navarro Michel, M. (2018). "La gestación por sustitución, ¿debe ser regulada? Y, en su caso, ¿cómo?" In: García Manrique, R. (coord.). *El cuerpo diseminado. Estatuto, uso y disposición de los biomateriales humanos*. Civitas, Thomson-Reuters, pp. 237-258.

Nora Lloveras, J. (2010). "El diagnóstico genético preimplantacional." *Revista de Bioética y Derecho*, no. 18, pp. 10-16.

Pinto Palacios, F.; Marcos del Cano, A. (2016). "'Bebé medicamento', protección de la salud y sistema sanitario público: una reflexión desde el principio de justicia." *Universitas*, no. 24, pp. 243-265.

Warnock, M. (2004). *Fabricando bebés. ¿Existe un derecho a tener hijos?* Gedisa Editorial. Bioética. Series edited by Javier Sádaba and María Casado.

6 The End of Life

1. INTRODUCTION[1]

The treatment of euthanasia poses problems that in order to be resolved collectively require broadbased, thorough social debate. Since the 1970s various surveys have been carried out in Spain, of both healthcare personnel and the general public. In all of them the percentage in favour of regulating euthanasia is somewhere in the region of 80%. Nevertheless, the various attempts at regulation have been unable to approach the subject with the necessary depth and the regulatory solutions have always turned out to be unsatisfactory or flawed.

In the media, information relative to the end of life periodically monopolizes most of the news about bioethics. Although this prominence sometimes gives way to interest in discoveries based on the genome, big data or artificial intelligence, the continual bombardment of news of cases of euthanasia makes it clear that the issue is still highly topical and it comes back stronger with each new case. In Spain the repercussions of the case of Ramón Sampedro are well known, and the film *Mar adentro* (The Sea Inside), based on the case, is one of the most outstanding on the issue.[2]

In a context in which death is increasingly medicalized,[3] the conflict appears initially between volition (respect for autonomy) and certain ideas about

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[1] This chapter is an update and a rewriting of the one written by M. Casado in the early 1990s, in *La eutanasia. Aspectos éticos y jurídicos*, editorial Reus, Madrid, 1994. It moreover incorporates considerations made by her in the *Document on the Right to End One's Own Life Under Certain Circumstances,* by the University of Barcelona's Bioethics and Law Observatory, Signo, Barcelona. 2004. On the legislation in the autonomous communities and advance directives documents, see López Baroni, M. J. (2005). *Bioética y multiculturalismo: políticas públicas en España (1978-2013). El hecho cultural ante la revolución biotecnológica*. Universidad de Barcelona, Ch. II.

[2] García Manrique, R. (2011). *La medida de lo humano: ensayos sobre bioética y cine*. Navarra: CivitasThomson Reuters. There are also some interesting films dealing with this issue, among them *Million Dollar Baby* and *Johnny Got His Gun*.

[3] Méndez, V. (2003). "El modo tradicional y el modo tecnológico de morir". *Revista ROL de Enfermería*. Also (2002), *Sobre morir. Eutanasias, derechos, razones*. Madrid: Trotta.

the right to life.[4] Multiple factors, however, play a part in it, including medical judgment and those derived from the patient's circles, those of a religious nature, those resulting from the distribution of resources, from the safeguarding of legitimate interests of third parties, and so on, which in many cases get in the way of determining what the patient's best interests are, and respect for his or her wishes. At present, the ends of medicine themselves are being questioned: prolonging life at any cost is not the goal of medicine. Even the Council of Europe says this.[5]

Respect for people's basic rights also implies being able to make decisions about one's own health. Respect for the person's autonomy in healthcare is a process that has been developing gradually: through the introduction of the requirement for informed consent, with the acceptance that competent people can exercise their right to refuse any medical treatment or action including so-called life support, and through the enactment of laws that regulate advance directives (living wills). This development must continue, giving these real content and admitting, moreover, the possibility that the free exercise of autonomy may also materialize through the right to end one's own life in certain cases. In other words, accepting what is commonly known as active voluntary euthanasia.

The discussion about the legitimacy of euthanasia must be tackled from a twofold point of view: as a matter of respect for people's autonomy, and one of solidarity with those suffering.[6] The initial reference in this discussion is the traditional invocation of the person's autonomy and dignity, because euthanasia is an individual and, by definition, autonomous decision. Also, because the harming of the rights of other subjects cannot be invoked, since, also by definition, that decision only affects two parties directly: the one requesting it and the one performing it.

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[4] In 2016, coordinated by Albert Royes, the collective book *Morir en libertad* was published, in which members of the Bioethics and Law Observatory compiled articles and documents published in recent years on this subject. As it states in the book's introduction, "The right to a dignified death, the right to be able to choose the moment and the way of putting an end to one's own life — having, in order to do so, the essential professional assistance for the purpose of avoiding more suffering — when the continuation of life is perceived and felt as something bad and not something good, hence the book's title", at www.publicacions.ub.edu/ref/índices/08395.pdf.

[5] Recommendation 1418/99 of the Parliamentary Assembly of the Council of Europe.

[6] CCNE, *Avis sur la fin de vie, ârret de vie, euthanasie*, of 27 January 2000, Paris. It can be consulted at www.ccne-ethique.fr/francais/avis/a_063.htm and CCNE, *Avis concernant la proposition de résolution sur l'assistance aux mourants...*, of 24 June 1991, Paris. It can be consulted at www.ccne-ethique.fr/francais/avis/a_026.htm#deb.

2. UNDERLYING VALUES: FROM THE SANCTITY TO THE QUALITY OF LIFE

It is often thought that there is a tendency to go from one system of protecting life that corresponds to the paradigm of its sanctity, to a system of protection that takes into account a more qualitative point of view:

> Sanctity is the distinctive trait of the tendencies that aspire to protect human life as such, without considering possible physical or mental deficiencies or their social usefulness. By qualitative orientation I mean all the aspects that do not describe life as inviolable or susceptible to valuation per se, but as something qualitatively adjustable or, in any case, not excluded a priori from all consideration with other interests.[7]

Professor Albin Eser considers that the widespread opinion that protection is in decline — "from the sanctity to the quality of life" — is to some extent a prejudice and that both principles ought to be combined as harmoniously as possible; furthermore, he attempts to ascertain when a particular legal system is more inclined towards a sacred or, on the other hand, a qualitative consideration of life, in doing so reviewing German criminal law. In any case, it does not seem surprising that life, traditionally considered to be sacred and inviolable, should be increasingly exposed to a qualitative assessment, and with this — as a necessary consequence — be compared and considered with other values.[8]

It is usual to agree that Christianity introduced the conditions for which the law went from a system of consolidation and stratification and of qualitative discrimination of human life to the consideration that, as a creation of God, every person is equal and all human life is sacred and inviolable per se, for oneself and for others, without taking into consideration its physical qual-

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[7] Professor Albin Eser of the University of Freiburg, director of the Max Planck Institute, is one of the best-known experts on this subject and his paper on the transformations of criminal law's protection of life, "Entre la santidad y la calidad de vida", the translation of which was published in the *Anuario de Derecho Penal* of 1984, p. 747ff, is fundamental for an understanding of the subject.

[8] On the contrast between the ethics of the sanctity of life and of the quality of life, Joseph Fletcher reaches conclusions different to those upheld by Eser when claiming that "traditional ethics based on the sanctity of life, which was the classic doctrine of medical idealism in its pre-scientific stages, must give way to the ethics of the quality of life. This occurs for humane reasons. It is the result of the successes of modern medicine, not of its failures". See the article by J. Fletcher, "The Sanctity of Life Versus the Quality of Life", from *Euthanasia*, in *Humanhood: Essays in Biomedical Ethics*. New York: Prometheus Books, 1979, pp. 149-158.

ity or social status. In neither Roman law, nor in Germanic law codes — and even less in earlier law codes — had this been so. The death of a slave was seen as a crime against property; and even reparations for the death of a person were graded according to his or her status, age and sex, something that by the way is also the case now in the amounts of compensation due to accidents established by law, and in the premiums and reimbursements for illness by private companies. Ancient philosophers did not consider human life a value as such, but it was linked to its social usefulness. Plato and Aristotle advocated demographic policy measures such as the exposure of infants or abortion. The influence of religious principles and canon law on the medieval legal system was thus the main reason for the acceptance of this idea of life as a value in itself, as included for example in the Caroline Law, the first criminal law code promulgated in Germany in 1532 by Emperor Charles V.

Nonetheless, to put things in their true perspective it is necessary to mention that not even in the frameworks of the greatest protection of life have exceptions to this principle, more or less striking or concealed, ever ceased to be made. The classic exceptions to the prohibition to kill, as Eser recalls, constitute important breaches in the protective fence of life and they include cases in which biological life was *ab initio* denied its human nature, and cases in which the death of a person was justified for different reasons. It is necessary to agree that, "by attempting to impose the protection of life through the destruction of life, the claim to its sanctity is suspended. By being able to destroy life for the safety of other legal assets, it becomes a ponderable object", although "the classic exceptions to the prohibition to kill represent only the reaction to an illegal aggression — at least from a typical-ideal perspective — where the life destroyed had already been staked previously. In this, legitimate self-defence, the death penalty and death in a defensive war are fundamentally distinguished from the cases […] in which the life destroyed is not an aggressor but a victim: termination of pregnancy, euthanasia and suicide". In these cases, life becomes a value worthy of being considered and even displaced by material interests or social needs. The quality of life comes before existence itself.

Similar problems arise in this respect with regard to both the beginning and the end of life, and expecting clear defining and delimiting criteria from medicine or biology would be illusory. The more these sciences progress, the more difficult it is to confirm qualitative leaps. This makes it even more necessary to establish a legal regulation and to develop serious reflection on the matter, if we do not wish to find ourselves reduced to the systematic adoption of a series of medical and pragmatic solutions, dictated by virtue of the circumstances, which, incidentally, is what has been happening up to now.

Although it is difficult to approach and study in detail the problem of whether absolute values and universal laws exist, and the real history of human beings, it must be acknowledged that life has never been a right of this sort. If it can be compared to other values, such as defence, sacrifice, punishment, and so on, why can't it be compared to the quality of it? Or to the will to live, with the imperative of volition? The aim is also to produce consideration of all these issues.

3. Classic but rather obscure distinctions: active/passive euthanasia and ordinary/extraordinary means

When analysing different legal systems from a historical perspective, one sees that, although it may be considered legitimate to put an end to somebody else's life for one's own good, this is not the case if the same act is performed for that person's own good. Likewise, one can put an end to one's own life for the benefit of one's fellow man or woman in an act of heroism — for example, saving a person who is drowning — but the same act would not be well thought of — on the contrary, it would be reproached — if one ends ones own life for one's own good (suicide). Punishments have even been established for suicide, a complete paradox and a true reflection of the unease that such issues usually give rise to. Illustrative examples are, in canon law, the refusal to bury people who have committed suicide in holy ground, or, in Roman law, the seizure of the inheritance by the state.

Leaving aside the subject of suicide and considerations of a legal and moral nature about it, as far as euthanasia is concerned this attitude is reflected in the different ways in which active and passive euthanasia are regarded. For some people killing is worse than allowing someone to die. Ignoring for the moment the legal questions, whose methods of reasoning are in some ways peculiar, is it true, from a moral point of view, that such a distinction exists?

The example put forward by James Rachels is enlightening, when referring to the case of babies with Down syndrome that moreover present congenital defects such as, for example, intestinal obstruction, which requires the baby to be operated on immediately in order for it to survive. In some cases, the doctor and the parents decide not to operate and to let the baby die: however, although it may be simple in a theoretical discussion to decide that these babies must be allowed to die, it is different when one observes how infection and dehydration slowly end the life of a child who could be saved. "I understand that there are people who are opposed to all kinds of euthanasia and insist that such children must live. I also understand why other people are in favour of putting down these babies quickly and painlessly. But what reason is there to allow dehydration and infection to weaken a tiny being for hours and days? The doctrine that allows a baby to dehydrate and languish, but prevents it from being given an injection to put an end to its life without suffering, is so obviously cruel that it needs no further refutation."[9]

In the proposed example, the reason why the relatively easy surgical operation to remove the intestinal obstruction is not performed is none other than Down syndrome, by reason of which the parents and the doctor are of the opinion that the best thing for the child is to die:

> But we see that this situation is absurd, regardless of the point of view that everyone adopts with respect to life and the potentials of these babies. If the life of such a child is worth preserving, then what difference does it make if it needs a simple operation? Or, if one thinks that it is better for such an infant to die, what difference does it make if it happens to have an obstructed intestinal tract? In either case, the question of life and death is being decided on irrelevant grounds. The key issue here is Down syndrome, not the intestines. The issue should be resolved, if it has to be, on this basis and not on something as irrelevant as whether or not the child's intestinal tract is blocked […].[10]

It is rather superficial to suppose that, because nothing has been done to hasten death, one is not a party to it. By not doing anything one is doing something: deciding what form of behaviour to adopt, just as in any action. Omission is consequently taken into account not just by the law, but in the moral evaluation of this behaviour.

In general, human beings feel a huge devotion for rules in themselves and an underlying fear of making important decisions individually without the backing of dogmatic guidance. This is the kind provided by systems of morality that establish prohibitions or taboos, indicating what must or must not be done without taking into account the consequences, simply because it is thus ordained, regardless of the results of such behaviour. Opposed to this kind of ethics — of duty — are systems of finalistic guidance that value the acts per-

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[9] *New England Journal of Medicine*, no. 929, 1975. This example is repeated as, among others, it is also collected by P. Singer in his *Practical Ethics* and M.D. Farrell repeats it in his article "La justificación de la pena en los casos de eutanasia: un análisis ético", in the *Anuario de Derecho Penal,* no. 21, 1983.

[10] Rachels, J., *op. cit.*, p. 47ff.

formed by the consequences obtained, according to whether they have served human values and to how they have done it; for them, the supreme good is happiness, human wellbeing, not sticking to the rules or important principles.

If actions and omissions must be equally important, why should this not be the case in the issue of euthanasia? If one thinks that killing is no worse than letting someone die, one must accept that active euthanasia is no worse than passive. Nevertheless, most people do not think this, and nor do the doctrines of the major religions, or the declarations of medical ethics, such as those of the British Medical Association, the American Medical Association, the World Medical Association, and the majority of the deontological codes of colleges of physicians.

An initial distinction is usually established between the acts that produce death decisively and positively and others that allow death to occur by ceasing to apply certain life support procedures that in medical terminology are known as "extraordinary means".

The traditionally accepted view starts by considering as indisputable that no one — a doctor, or anybody else — can intentionally terminate the life of a patient. At the same time, it is accepted that there are other cases in which it is permissible to cease to use certain types of means to maintain life although this may shorten it and even cause the patient's death. This approach may be called inconsistent, but it is the one that prevails in normal clinical practice.

Doctors have always taken part in making decisions about the end of life and it is currently considered good practice to limit, suspend or not begin treatment in certain circumstances even though this may lead to the patient's death: it is what is usually called limitations on therapeutic efforts, limitation of treatment or, simply, passive euthanasia. In any hospital, every day decisions are taken to suppress treatments when the agony is prolonged, with the said interruption resulting in the patient's death. The tactic of letting someone die is the solution used given that, with what is now available, it is indefensible to always do everything technically possible to maintain biological life. Unless one is absolutely pro-life, the dignity, the wellbeing and the wishes of the person in question must be taken into account; this means taking into consideration the quality of life and not just the mere biological survival of extreme prolifism.

With regard to the use of ordinary or extraordinary means, it is equally difficult to establish a fixed distinction, since the means that are now totally habitual were considered to be extraordinary not long ago; moreover, what for some cases is extraordinary will not be in others. Several factors must be taken into account, such as the possibility of success, the level of quality of the life that one is trying to preserve, survival time, the suffering caused to the patient and his or her family by the treatment and the cost of the therapy, not just to the individual and his or her family but also from the point of view of the group, bringing into play a matter of so-called health economics. All these factors must be pondered together, and although some are objectively ponderable, others will depend on the patient's subjective situation, which is always more difficult to assess. Paul Ramsey says that:

> [...] ordinary means for the maintenance of life are all the medications, treatments and operations that offer a reasonable hope of benefit for the patient and which may be obtained and used without entailing expense, pain or other excessive problems. Extraordinary means for maintaining life are all the medications, treatments and operations that cannot be obtained without entailing expense, pain or other excessive problems, or which, if used, would not offer a reasonable hope of benefit.[11]

None of these definitions has as yet provided a criterion that may be used to determine whether a treatment is obligatory or not:

> But, when is the cost too much? Is $10,000 too much? If it saved the life of a young woman and returned her to perfect health, $10,000 does not seem excessive. But if it only prolonged the life of a diabetic suffering from cancer for a short while, $10,000 might be excessive. It is not just a case of what is excessive varying according to the case. It is that excessive *depends* on whether prolongation would be beneficial for the person in question. Secondly, how can we tell if a treatment will benefit the patient? Remember that we are talking about treatments for the prolongation of life; the *benefit*, if there is one, is the continuation of life. Whether the continuation of life is a benefit or not will depend on the details of each case. Once again, the question lies in the fact that, to decide if the treatment to maintain life is beneficial, we must *first* decide whether, for the life that is at stake, such a prolongation will be good.[12]

Ultimately, it is a question of pointing out that both the distinction between ordinary and extraordinary means and active and passive euthanasia, and even the introduction of intentional factors as determinants in the assessment are rather unclear and even irrelevant. It seems obvious that, morally,

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[11] Ramsey, P. (1992). "Más distinciones impertinentes." In: Baird, R. M.; Rosenbaum, S. E. *Eutanasia: los dilemas morales.* Barcelona: Martínez Roca, Ch. 8, pp. 68-59.

[12] Rachels, J., *op. cit.*, p. 71ff.

active and passive euthanasia are one and the same, and if one is declared to be acceptable, the other must also be; and active euthanasia might even be preferable sometimes.

The arguments against this approach insist on the fact that in passive euthanasia the doctor does nothing to cause the patient's death, since the sick person ends up dying of the disease he or she was suffering from. But, as has been said, not supplying a medicine is a deliberate omission, as conscious as the opposite, and therefore equally attributable to the person who does it.

4. The terms of the debate and the question of dignity

The conceptual confusion still underpinning the debate about euthanasia is without doubt closely linked to the ambiguity existing around the different meanings attributed to the word euthanasia. According to some the term refers to any medical treatment that shortens the life of a sick person and it is also associated with the act of letting people die. For others, it is equivalent to compassionate homicide, or to homicide for the good of the victim. For some it is identified with homicide at the request of the person who is dying and helping someone to commit suicide. And there are also some who understand it as the act of putting an end to the lives of undesirable people, or as causing the death of those who are suffering.

The consequence of these different meanings of the term euthanasia, with different and even divergent ethical and legal appraisals in which descriptive and prescriptive definitions are mixed up without distinction, is that when euthanasia is discussed it is not at all obvious what the debate is about. The great variety of meanings of the many definitions devised in order to distinguish between the different types of euthanasia — active and passive, direct and indirect, voluntary, not voluntary and involuntary — have given rise to a series of types that are no help when obtaining criteria for making decisions in the specific cases. As these classifications are not applicable to all the different definitions of euthanasia, and as they are liable to be combined with one another, their use has generated a terminological complexity that makes discussing the different problems underlying the issue of euthanasia even more difficult.[13]

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[13] Méndez Baiges, V. "La muerte contemporánea: entre la salida y la voz", in *op. cit.* Royes (2016). *Morir en libertad*.

Euthanasia is an action in two acts, each of which has a different protagonist. In the first one, the protagonist is the sick person who is suffering from a serious disease that would necessarily lead to their death or which causes them permanent suffering, difficult to bear, and it is this person who takes the ethically legitimate decision to end his or her life peacefully and in a dignified manner. This sick person has free will, or they had it when they signed an advance directives document. This first act is truly basic and, in turn, it is the basis of the second.

The second act consists of the medical intervention that causes death quickly, efficiently and painlessly, and it would in fact be illegal if the existence of the first act could not be confirmed. But it is necessary, because it complies with the sick person's free decision. For this wish for a good death to be fulfilled, the doctor's help is necessary, given that, in accordance with current knowledge, drugs will have to be prescribed and administered correctly. And the reason why this medical intervention is required is practical, since the professional knowledge will ensure that death occurs as peacefully as is hoped for.

The reasoning that upholds the sick person's free decision is moral autonomy. A law that tried to impose euthanasia on all who are incurably sick and in pain would not be legitimate, but a law that accepts it in certain very precise cases and includes the necessary precautions to prevent possible errors in either of the two acts that contribute to it would be.

The debate is open: should a terminally ill patient's wish to die be respected? Does one have to collaborate in it? What treatment should be used when the moment of death draws near? Who can decide if the patient has not expressed his or her wishes and is unable to do so? Some of the greatest difficulties in this area arise when deciding on the interruption of treatments in sick people with irreversible disorders of consciousness who are unable to express their wishes and who have not made previous arrangements. Not forgetting the special case that is the persistent vegetative state in which, upon having to decide on someone's behalf, one may choose to resolve it by attributing to the situation a significance that takes into account the presumed wishes of someone who is no longer competent. This frequently turns the issue into a problem of proof, as happened in the case of the famous Nancy Cruzan sentence.

The assessment of the subject's quality of life can also be used as a criterion, or trying to guess what their wish would have been, as happened previously in the case of Karen Quinlan. It is a thorny issue, because on top of medical and biological opinion one would have to add an assessment of the subject's quality of life from the human and personal point of view, but which, in these cases precisely, cannot be established. The appraisal of the patient's best interests can also contribute new directions and arguments, but it may actually be for the best, as happened in the case of Tony Bland, if these patients do not have interests.[14]

The approach is different in Anglo-American countries, staunch defenders of autonomist criteria, and in Latin countries, which have shielded themselves behind the pretext of respect for life. One has to bear in mind that Catholic tradition is immersed in a general delegation of responsibility to other more qualified hands in the technocratic treatment of conflicts. Whereas in the Protestant tradition, the basis of the current thinking that we call Anglo-American, people are far more accustomed to deciding for themselves. The habit of free examination has left different marks of the custom of always acting with dogmatic guidance.

In our opinion, this discussion is a matter of extreme situations. In the new millennium, the debate about euthanasia should be held from a twofold point of view: as a question of respect and of solidarity. The attitude to euthanasia is a true test of validation of the acceptance of the principle of autonomy; a principle in which we claim to concentrate not just moral decisions but the general life of our society (which at least agrees to be defined as liberal).

If we truly respect someone else's autonomy, this respect must be shown in the acceptance of decisions that we do not necessarily share.[15] Accepting and respecting opinions and behaviours of which we approve is not difficult in the slightest. The test of tolerance, in the most positive and active sense of this term, comes with our consideration of behaviours whose reasons we do not share.

Why, then, is the issue of euthanasia still approached so virulently in some areas of society? In our opinion, the reason lies in the enormous burden of ideology attached to this debate, the reason why certain attitudes seek refuge in maximalist and, in many cases, intolerant attitudes. Among the detractors of euthanasia one frequently senses an attitude that leads to a clash of absolutes (of course this is not the only area in which these attitudes appear), whereas the defenders of the right to die in freedom approach it as a question of respect.

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[14] The different paradigmatic cases in the discussion on euthanasia have been opening up the debate about the possibility of withdrawing life support measures. First the respirator, in the case of Karen Quinlan (1975); then the nasogastric tube, in that of Nancy Cruzan (1983), and later, with that of Tony Bland (1993), in which the House of Lords — as the highest court of appeal — ruled that Tony "had no interests". See Singer, P. (1997). *Repensar la vida y la muerte. El derrumbe de la ética tradicional*. Buenos Aires: Paidós, pp. 67-87.

[15] An essential work of reference is Dworkin, R. (1994). *El dominio de la vida. Una cuestión acerca del aborto, la eutanasia y la libertad individual*. Barcelona: Ariel.

Both sides invoke the defence of human dignity, but they obviously understand it differently. There are two main schools of thought when interpreting and making sense of dignity, and even the notion of human rights: the Christian and the secular. If the discussion is not explained, it may become a dialogue of the deaf: agreement is impossible if the same words mean different things.

Although we referred above to the traditional invocation of the person's autonomy and dignity, resorting to the framework of the general approach, we have to complete this analysis by considering the other approach to the problem of euthanasia mentioned at the beginning and which may be more profitable: solidarity and respect.

Speaking about this sense of compassion does not mean understanding this concept paternalistically, but it appeals to a supportive idea of people's relationships, to a view of the problem that accepts exceptional openings for exceptional cases. Moreover, it is a case of circumscribing the field of agreement in accordance with a strict definition of the term, linked to the subject's request and to the meeting of requirements that guarantee volition.

I believe this is a good route to agreement between habitually opposing positions. To end with, I would also like to submit for the reader's consideration two questions underpinning any bioethical agreement and which, moreover, may come prior to it: first, the specification and limitation of the objectives that can be achieved and their provisional nature; of course this is more awkward and insecure than being comfortable with eternal truths, as it demands greater responsibility due to decisions made freely. And second, remembering explicitly that we can agree that a type of behaviour is correct although we may not agree with the reasons for it. Only in this way is it possible to construct specific one-off agreements, rather than empty generic consensus.

Having thus clearly shown the implications of this important social debate, it is now time to show the contribution that legal considerations can make to it.

5. EUTHANASIA IN RELATION TO FUNDAMENTAL RIGHTS

Being able to freely choose a dignified death as an individual right is a demand that is considered appropriate to modern societies that take a secular approach when dealing with the problems of death. The right to a dignified death has been named as one of the fundamental rights, as a question that affects the quality of life, third-generation rights that may be connected to social rights, relative to health, including it as one of the rights of the patient. In the General Healthcare Law and Law 4/2002, the basic regulator of patient autonomy and of rights and responsibilities in matters of information and clinical documentation, the patient's informed consent is established as a general principle with regard to treatments that he or she must follow and their possible interruption. The said law also includes various declarations of sick people's rights, such as the right to control one's own destiny, bodily integrity, religious assistance according to one's beliefs, privacy, and in sum, comprehensive care given by qualified professionals.

It is not difficult to link these concepts to that of the dignity of human life, basic in the Spanish legal system. The constitution mentions human dignity, along with freedom, as one of the most important values of our legal system. In article 1.1, and in 10.1 which protects the dignity of the person and their right to freely develop their personality, or in 16.1 which guarantees ideological freedom, or in article 15, the fundamental principles that must be taken into consideration for the purposes of establishing a correct relationship between the prohibition on killing and the right to individual self-determination are established.

In short, the acknowledgement of the right to life in our system is designed to provide guarantees: against the state and against other citizens. It is moreover a personal right that is exercised according to the wishes of its holder. It is not an absolute right: the right to life may clash with other rights and it must be duly considered.

From a strictly legal point of view, it is not possible to place the right to life above the freedom of the individual. The concept of personal dignity is basic in the interpretation and determination of the scope of the fundamental rights recognized in the first title of the constitution and it seems difficult to impose an idea of the right to life such that it is incompatible with human dignity. From the analysis of the constitution we learn that the essence of rights and freedoms lies in the free development of the personality, in the person's full development and improvement, individually and socially. Therefore, all legislation must respect all the rights and freedoms expressed in the other chapters of the constitutional title.

One must bear in mind that the Criminal Code must be applied in the light of the constitutional principles, since it is these that determine which legal assets are deserving of legal protection. The consideration that the constitution has a direct and immediate normative value leads us to consider that the higher values it recognizes, such as freedom, equality and human dignity, must inform the entire legal system and, consequently, they must also be considered informative principles and limits of criminal law. As a result, the treatment by criminal law of certain behaviours liable to be thought of as euthanasia forces us to make an interpretation in accordance with that laid down in fundamental law.

In the case of direct active euthanasia — taken to mean executive acts that cause an effective shortening of the patient's life — the application of the Criminal Code may class such behaviour as manslaughter (articles 138 and 142) or murder (articles 139, 140 and 141), depending on the circumstances that are appreciated. However, the presence of the victim's consent, accompanied by the requirements of "his or her express, serious and unequivocal request, in the event that the victim was suffering from a serious illness that would necessarily lead to death or would produce severe permanent suffering, difficult to bear", places direct and voluntary active euthanasia within the type included in article 143.4 of the Criminal Code, for which an extenuation of the sentence by one or two degrees is envisaged.

This law, which is considered to be a compromise solution, was adopted in our code after an intense social debate, since in the previous law such behaviour represented executive assistance for committing suicide, with it being possible to take the victim's wish to die, their consent, into consideration as an extenuating circumstance. In cases where this wish to die could not be expressed until the last moment, the courts could appreciate the existence of a merciful motive to extenuate the sentence. This implied, in certain cases, that it was necessary to force the legal instruments to achieve a materially just solution; this includes a degree of chance in the application of the law that is not at all desirable and which goes against all the repeated wishes for legal certainty that are characteristic of the rule of law.

6. Legislation in the autonomous communities of Spain

The fact that the Spanish state has exclusive competence in criminal law has caused some autonomous communities to regulate this subject with active euthanasia as the horizon, but without being able to recognize this right due to the fact it does not fall within the scope of their powers. For this reason, efforts have been focused on regulating the right to a dignified death within the reduced framework in which it was possible, as in Andalusia, or on proposing a state-wide change to the Spanish parliament, as happened in Catalonia.

Beginning with the Spanish autonomous communities' lack of competence to be able to regulate active euthanasia, we are going to analyse the three most noteworthy attempts to regulate assisted suicide. We shall study the Andalusian Law of Dignified Death, the bill for the decriminalization of euthanasia and assisted suicide in Catalonia, and the way in which the living will has been developed in different autonomous communities.

1) *Law of Dignified Death in Andalusia*. In 2010, Law 2/2010, of 8 April, was passed, on rights and guarantees for the dignity of the person in the process of dying in Andalusia. The characteristics that we can highlight in this law are the following:

1.1. In 2010, the year the said law was passed, the PSOE, a social democratic party that on more than one occasion has positioned itself in favour of regulating active euthanasia, was in power in both Spain and Andalusia. In fact, the Andalusian law was seen as a test for observing how viable a more ambitious state-wide law might be. José Luis Rodríguez Zapatero's Socialist government, in power in Spain from 2004 to 2011, might well have tackled the subject had it not been for the economic crisis that in 2011 forced it out of government before time (we should remember that during its term in office other social advances were achieved, such as the voluntary termination of pregnancy or same-sex marriage, unthinkable in Spain a few years earlier).

1.2. The law we are examining was achieved through consensus between the two main political parties in Andalusia, the PSOE and the Partido Popular, a Christian democratic party opposed to regulating active euthanasia. For this reason, the content of the law is rather ambiguous and the end result bittersweet.

Indeed, for the PSOE, the law was considered to be an advance because it regulated, within the framework of the state, "dignified death". But the PP also valued the law positively because it regulated what was already being done and at no time did it ask awkward questions. In sum, the fact that both parties considered themselves to be the victors shows the true limits of this law.

1.3. The law was inspired by or was the consequence of two cases, Leganés and Echevarría, massively reported in the media.

The Leganés (Madrid) case began with an anonymous tip-off that accused a group of doctors at Severo Ochoa Hospital of causing the death of more than 400 people through malpractice in the sedation of terminally ill people. After two years of investigations, the courts closed the file on the case and decreed that was there no crime, nor was there any malpractice. In the meantime, there were wrongful dismissals, groundless rulings, libels blown up by the more conservative newspapers, and so on, which generated great uncertainty in healthcare personnel, not just in Madrid, but in the whole of Spain, since it transmitted the idea that anyone could find themselves mixed up in a media witch-hunt such as this one.

The Echevarría case is based on the story of a woman who was connected to apparatus to keep her alive in a religious hospital in Andalusia. Both the woman and her family asked for her to be disconnected. Due to the refusal of the healthcare personnel, who belong to a religious order, she had to be taken to a public hospital. After a bitter debate, in which several rulings were required, she was disconnected. Although the Consultative Board of Andalusia voted in favour of disconnecting the woman, a single dissenting opinion against it was issued that stated the following:

> Advance directives thus come within the cases of healthcare to avoid any unwanted therapeutic cruelty at the end of life. But under no circumstances can they justify that a patient, in full possession of her mental faculties, […] could request "that they let her die painlessly, after being sedated, and that she be disconnected from the artificial breathing mechanisms". The case we are looking at here — suspension of the treatment with mechanical ventilation that will necessarily result in death, being previously sedated for it, at the specific request of the patient herself — is not in any way envisaged in the current legislation.[16]

In other words, at the time this occurred, there was no state or autonomous law on how to proceed in this kind of case, or at least the matter had not been regulated explicitly. For this reason, the law in Andalusia that we are commenting on tried to fill this gap in the law, partly to specify patients' rights (principle of autonomy), and partly to provide legal coverage to the healthcare personnel who take decisions in such difficult situations (legal certainty).

1.4. The law did everything it could to avoid using the term euthanasia. Thus, in the preamble to it we can find the following paragraph:

> On the contrary, the refusal of treatment, the limitation of life support means and palliative sedation *must not be defined as acts of euthanasia*. These acts never deliberately seek death, but to alleviate or avoid suffering, respect patients' au-

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[16] Dissenting opinion formulated by councillor Sánchez Galiana to the ruling of the Permanent Committee of the Consultative Board of Andalusia on the Optional Consultation presented by the Minister for Health of the Junta de Andalucía, in Bensusan Martín, P. (2007). "Problemas jurídicos actuales sobre la vida y la muerte." *Revista Andaluza de Administración Pública*, no. 68.

> tonomy and humanize the process of death. Accepting the right of sick people to refuse a particular healthcare intervention is merely *showing exquisite respect for personal autonomy,* for everyone's freedom to manage their own life, assuming the consequences of the decisions they make. [Our italics.]

As can be observed, the term euthanasia (active, passive, direct, indirect, etc.) was treated as a taboo, so consensus and politically correct expressions prevailed above all else with the aim of getting the law passed.

1.5. The law employs a catalogue of definitions to explain the legal significance of some acts. Thus, the law defines therapeutic obstinacy as a way of prolonging biological life without the real possibility of improvement or recovery (what is known as dysthanasia); it defines the "limitations on therapeutic efforts" as the withdrawal or non-introduction of medical treatment, due to the fact that this treatment will not result in the patient's improvement (what is known as passive euthanasia); it defines palliative sedation as the administration of drugs to relieve the agony (what is known as indirect euthanasia); and, lastly, it grouped the series of medical interventions aimed at treating a terminal illness and reducing the suffering under the expression palliative care.

2) *Law of Decriminalization of Euthanasia and Assisted Suicide in Catalonia*. In 2017 an initiative was promoted in the Parliament of Catalonia for a proposition to reform Organic Law 10/1995, of 23 November, in the Criminal Code, to be tabled in the Spanish parliament, for the purposes of decriminalizing euthanasia and assisted suicide. The parliamentary initiative had the participation of members of the University of Barcelona's Bioethics and Law Observatory, a body that in 2003 had published a report entitled *Document on the Patient's Right to End His or Her Own Life Under Certain Circumstances: Declaration on Euthanasia*, which included the general lines that were later transcribed to the Catalan bill.

In this case, the purpose of the proposal was not a law exclusively for Catalonia but to modify the Criminal Code for it to be valid for the whole of Spain. It was proposed to add a paragraph to article 143 of the Criminal Code with the following wording:

> Sole article:
>
> Modification of section 4 of article 143 of Organic Law 10/1995, of 23 November, of the Criminal Code, which will be worded in the following terms:

> "4. Notwithstanding the provisions of the foregoing paragraphs, upon the express, free and unequivocal request of a person who has a serious illness that would necessarily lead to their death, or an incurable disease that will cause them serious physical or mental suffering and which is deemed to be permanent, anyone who causes or cooperates with acts necessary for the safe, peaceful and painless death of this person, will be exempt from responsibility, in the framework established by the law."

The parliamentary initiative advocates the right to a dignified death and proposes to create the suitable institutional framework so that a citizen may make the informed and autonomous decision that most suits their personal worldview. For this, the proposal uses as a model the legislation in the Netherlands; it proposes to organize a palliative care unit that will be on standby 24 hours a day, 7 days a week; it requires the initial and comprehensive training of the staff working in it; it promotes the creation of an observatory to permanently gather the information necessary to improve the service, etc.

Lastly, the initiative provides important information on how the sensibility of Spanish society has changed in recent years, in the sense of being more favourable to a change in the law such as the one being promoted. Thus, in the legislative initiative a survey carried out in 2015 by *The Economist* in 15 countries is mentioned, where it was reported that 78% of those interviewed were in favour of assisted suicide being regulated in Spain, as opposed to 7% who were against it.

7. The legal framework of advance directives[17]

The Council of Europe's Convention for the Protection of Human Rights and the Dignity of the Human Being with Respect to the Application of Biology and Medicine, of 1997, came into effect in Spain in the year 2000 with the resulting obligation of the state to adapt the current laws to its provisions. It is the international legal reference on advance directives: "previously expressed

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[17] See Casado, M.; Royes, A. (eds.) (2010). *Repercusión e impacto normativo de los Documentos publicados por el Grupo de Opinión del Observatori de Bioètica i Dret sobre las voluntades anticipadas y sobre la eutanasia*. Barcelona: Signo, at www.bioeticayderecho.ub.es/documentos. Also, Royes, A. "El consentimiento informado y los Documentos de Voluntades Anticipadas." In: Casado, M. (ed.) (2007). *Nuevos materiales de bioética y derecho*. Mexico City: Fontamara, pp. 159-176. Also, along the same lines, López Baroni, M. J. (2005). *Bioética y multiculturalismo: políticas públicas en España (1978-2013). El hecho cultural ante la revolución biotecnológica*. University of Barcelona, Ch. ii, at http://diposit.ub.edu/dspace/bitstream/2445/66784/1/MJLB_TESIS.pdf.

wishes will be taken into consideration, with respect to a medical intervention, by a patient who, at the time of the intervention, is not in a situation to express his or her wishes" (Art. 9). At the same time, the Convention establishes generally that any intervention in the sphere of healthcare requires the free and informed consent of the person affected, which may be revoked at any time. It is a case of giving appropriate information about the purpose and the nature of the intervention, and about its dangers and consequences. Both the Spanish state and the autonomous communities have modified or enacted different laws to adapt not only to the precepts of the Convention, but also to respond to a social demand and adapt the law to a reality framed in a process of the democratization of rights in the field of healthcare: the transition from medical paternalism to autonomy in healthcare, with its unquestionable advantages and its imbalances through practice.

The enactment of Law 41/2002, of 14 November, the basic regulator of patient autonomy and of rights and responsibilities in matters of information and clinical documentation (LAP), paved the way towards the acknowledgement of the right to decide, to refuse a treatment or not to be informed, and to clearly state in writing — and in advance, that is, through advance directives — what actions are permitted or refused by a person, patient or user of the health system when they are unable to express their wishes themselves. The establishment of this new model of relationships (between healthcare professional and user or doctor and patient) is not only determined by the abovementioned Law 41/2002, although it is true that it is the first to include the possibility of issuing advance directives (Art. 11).[18] A precept developed in due

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[18] Article 11. Advance Directives.

1. Through the advance directives document, an adult, capable and free, expresses their wishes in advance, for the purpose of these being complied with when they reach situations in whose circumstances they are incapable of expressing them personally, about the care and treatment of their health or, after their death, about the fate of their body or the organs in it. The grantor of the document may moreover designate a representative so that, when the time comes, he or she may serve as their interlocutor with the doctor or the healthcare team to ensure compliance with their advance directives.

2. Every health service shall regulate the proper procedure so that, when the time comes, compliance with everyone's previous instructions, which must always be in writing, is guaranteed.

3. Advance directives in contravention of the legal system, the *lex artis*, or those that do not correspond to the de facto situation that the interested party may have foreseen at the time of expressing them will not be applied. A reasoned record of the annotations related to these directives will be kept in the patient's clinical records.

4. Advance directives may be freely revoked at any time in writing.

5. For the purposes of ensuring the effectiveness throughout Spain of the advance directives expressed by patients and formalized in accordance with the provisions of the legislation of the respective autonomous communities, the National Register of Advance Directives will be created in

form by Royal Decree 124/2007, of 2 February, by which the national registry of advance directives and the corresponding automated personal data archive are regulated.

Moreover, article 9 of the Convention avoids using terms or expressions, such as euthanasia or living will, which might cause controversy. After it came into effect in Spain, in 2000, a controversy arose over the name of the document that included these wishes, which is worth commenting on.

There are three expressions — *instrucciones previas* (previous instructions), *declaración de voluntades vitales anticipadas* (advance directives) and *testamento vital* (living will) — that formally, and a priori at least, mean the same thing, since the regulation of assisted suicide in Spain is the same for the whole country, given that the state has competence in criminal law. Nevertheless, the autonomous communities and the state chose different formulas according to the ideology of the party or parties in power and, therefore, to the degree of tacit desirability of the regulation of assisted suicide.

Thus, the autonomous communities most opposed to active euthanasia used the expression *instrucciones previas*, with which they transmitted the idea that the patient informs the healthcare personnel of their wishes, but under no circumstances must these prevail over the *lex artis*. This is the formula most opposed to assisted suicide, as it gives healthcare personnel control to the detriment of the patient. It was, for example, the formula the Spanish state adopted when José María Aznar of the PP was prime minister in 2002.[19]

The autonomous communities most prone to regulating active euthanasia used the expression *testamento vital*, for its connotations clearly favourable to the patient's wishes being respected above all else, including, if possible, assisted suicide. It is the most militant formula, because it reinforces the importance of the citizen's wishes, which are no longer mere instructions but something more serious, a will.

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the Ministry of Health and Consumer Affairs, which will be governed by the laws that are determined in due form, by agreement of the Inter-territorial Board of the National Health System.

[19] Law 41/2002, of 14 November, basic regulator of patient autonomy and of rights and responsibilities in matters of information and clinical documentation. Article 11.1 establishes that "Through the advance directives document, an adult, capable and free, expresses their wishes in advance, for the purpose of these being complied with when they reach situations in whose circumstances they are incapable of expressing them personally, about the care and treatment of their health or, after their death, about the fate of their body or the organs in it. The grantor of the document may moreover designate a representative so that, when the time comes, he or she may serve as their interlocutor with the doctor or the healthcare team to ensure compliance with their advance directives." 2. "Every health service shall regulate the proper procedure so that, when the time comes, compliance with everyone's previous instructions, which must always be in writing, is guaranteed."

Lastly, an intermediate expression between the two is the *declaración de voluntades anticipadas*, which has been used above all when there has been no wish to be too controversial about the issue, but at the same time the intention was to make patient autonomy important. The case of Andalusia is paradigmatic. In 2003 its Socialist government promoted a law of *declaración de voluntades anticipadas*, due to the fact that the PP, opposed to this kind of document, was in power in Spain, and they mutually challenged each other's bioethics legislation in the Constitutional Court. But in 2010, Andalusia modified its legislation and called the said document a *testamento vital*, in a context in which the Socialists were also in power in Spain and it seemed that it would at last be possible to make progress in the regulation by the state of active euthanasia.[20]

Another significant example of the ambivalence of this formula is that of the Balearic Islands, as it called its document a *declaración de voluntades anticipadas* with the warning, if there was any doubt, that "the law does not enshrine, under any circumstances, direct active euthanasia".[21]

In conclusion, and as we can observe, the three documents are cloaked in ideological connotations. In fact, none of the three can differ in its content, since active euthanasia is still prohibited in Spain, but in some way the vocabulary used (instructions, declarations, will) tells us tacitly what is the attitude to assisted suicide of those promoting the law. The culmination of political correctness is the European Convention on Bioethics, which speaks to us of "previously expressed wishes", in the hope of pleasing everyone.

8. The right to live (and die) in freedom

Many of the moral and legal discussions about the right to die that society is presently having are largely motivated by what is understood by the term euthanasia, which has gradually acquired the specific nuance of a medical act necessary to make death easier when requested by the sick person or, even, the connotation of mercy killing. Where euthanasia is concerned terminological

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[20] Law 5/2003, of 9 October, of The Declaration of Advance Directives in Andalusia, was completed with Law 2/2010, of 8 April, of Rights and Guarantees of the Dignity of the Person in the Process of Dying. In the law of 2010 the expression "living will" is used, equating it expressly in a glossary to the "declaration of advance directives".

[21] Preamble to the Law of Advance Directives of the Balearic Islands, Law 1/2006, of 3 March, LIB 2006\77.

precision is essential; this also occurs in most areas of knowledge: conceptual delimitation is one of the most enlightening spheres of reflection for scientists and philosophers, and it moreover constitutes a meeting place for all.

Depending on what euthanasia is considered to be, people will be prepared to accept it or not; depending on whether or not it is possible to establish a clear, precise meaning that delimits this conceptual field, it will be possible to reach agreement about the different ways of tackling it and it will consequently be feasible to draft a precise regulation that will provide the longed-for legal certainty without being detrimental to freedom and human dignity. Despite what certain initial coincidences might suggest, in this field things are neither clear nor easy. This is shown by the intense discussion in contemporary society about euthanasia, the sense or not of its legal regulation and, where appropriate, specific formulas and legislative articles. Pope John Paul II even declared that euthanasia is the big issue of the late twentieth century. Sharing, moreover, many of the fundamental problems that affect the issue of abortion, the problems with euthanasia are the kind that at any moment could affect each and every one of us — we all know that, where death is concerned, the ratio is still one per capita.

There are conflicting legal assets in the issue of euthanasia and this necessarily means that the choice of prioritizing one over the others entails weighing them up. The different approaches point to the existence of various possibilities of assessing the underlying interests and the priorities in their protection. The same thing happens with other manifestations of legal tensions, for example in the conflict between freedom and equality, or in the clashes between the right to information and to privacy that often cause so many disputes in the media, as is well known.

The greatest difficulty lies in making the right to a dignified death — which means not receiving inhuman or degrading treatment, the refusal of treatment, self-determination and the right to decide about one's own body, freely ending one's own life, privacy — compatible with an idea of the right to life that, in practice, would like to be absolute, as far as euthanasia and abortion are concerned, but which, on the contrary, accepts consideration in its clash with different and, occasionally, merely material interests.

This idea of the right to life, even against the person's wishes, must give way to ideas more in keeping with the secular nature of the state and with respect for the right to self-determination, bearing in mind the importance that the law attaches to the consent of the interested party and which in our system is far clearer than the concept based on guaranteeing the right to live at any cost. This does not in any way mean that the guarantees must be weakened, but that it is necessary always to consider that they are established in favour of — and not against — the person who has the right to be respected, in all senses.

Just as in the case of abortion, legislators have established a series of instances in which it is considered that, given a series of specific pre-established circumstances, certain behaviours will not be punishable, although they may in fact be wholly typical, in the case of euthanasia the sick person's wishes could be taken into consideration to establish either a cause for justification, or include an absolutory excuse, owing to the existence of a conflict of interests. These solutions would enable the courts to appreciate, in each case that came before them, whether or not there was an actual case of euthanasia, and they moreover have the precedent that the law already envisages similar treatments not just for abortion but also in other cases of a conflict of values, as in theft between members of the same family.

The law must have a coherent response to enable it to provide a solution to the real problems that arise in society, no matter how new, unforeseen and controversial they may be, and even though it is foreseen that the legal solution adopted may be conflictive and even insufficient. It is, in sum, a case of regulating the existing reality, not a detached ideal situation.

Just as happened with issues that were in principle very problematic, like the reiterated example of divorce and abortion, or transplants, assisted reproduction and genetic manipulation, a complete legal regulation of euthanasia is something that must be tackled without delay, as it would make it possible to avoid immeasurable human suffering and help to clarify situations for which the legal response is anything but clear.

The death of Ramón Sampedro gave us a sad example of the true nature of the problem: after a long, complicated journey through the national and international courts of law, the tragic occasion seems to have arisen for which the crime defined in article 143.4 could be used for the first time.

It is known that the power of the law as a factor of social change is limited, but it exists, to a certain extent at least, and it must try to guide these changes in the direction that the majority of society demands, bearing in mind also that social issues never stand still.

Volition is, in any case, the key aspect of this regulation that should be established, respecting the right of doctors and healthcare personnel to conscientious objection, to participating in such acts by informing the patient of their right to change doctors, and enacting laws to make it easier for them to exercise their right to decide, while safeguarding their right to live, if they so wish. This law must pay special attention to overcoming problems derived from the possibilities of manipulation of consent and, in such situations, of any kind of abuse aimed at obtaining illegal financial gain, by establishing that, in the event of this happening, such behaviour is punished appropriately. All these problems with legislative policy are complex and difficult to resolve but they are by no means unresolvable if they are tackled with the necessary rigour and respect.

9. Palliative care

Any regulation of euthanasia has to be extremely careful also with regard to respecting the rights of the terminally ill who do not wish to resort to euthanasia or hasten the moment of death.

In this respect, it would be advisable to work for the introduction of palliative care units to attend to the terminally sick, beyond recovery, who require technical care that relatives are unable to provide and which, moreover, needs the human dedication so necessary at such a time.

The best-known initiative of this kind are the British hospices, centres where terminal patients are looked after in a family atmosphere, but which are equipped with every facility to be able to attend to the needs arising due to pain.

This hospice movement began in the UK in 1948, thanks to the efforts of Dr Cicely Saunders at St Thomas's Hospital. Twenty years later, in 1967, it became a symbol of the best possible care for the terminally ill with the creation of St Christopher's Hospice. In the 1980s, the number of hospices increased and, moreover, new ways of applying their principles appeared, such as hospitalization units known as palliative care units within large hospitals, or home care teams, those of support and control of the symptoms, and day units which, maintaining the same principles of action, attempt to reduce the cost of these programmes. This tends to rise sharply due not just to what they represent in themselves, but to the greater staff numbers needed by these programmes: degenerative diseases, ageing of the population, the rise in the number of cancer and, even more, AIDS sufferers.

In Spain, some hospitals are equipped with palliative care units organized with a similar philosophy to that of the hospices system, and which are growing in importance. There is also the Spanish Society for Palliative Care.

The headquarters of the Catalan-Balearic Society for Palliative Care is in the College of Physicians of Barcelona, whose statutes consider the institution's main objective to be care of the physical, emotional, social and spiritual aspects of people with terminal diseases, without the reasonable possibility of responding to treatment, whether caused by cancer, AIDS or any other chronic and progressive illness. It operates along the same lines as its counterparts, the Association for Palliative Medicine of Great Britain and Ireland, or the International Association for Hospice and Palliative Care, and it is extremely active.

Several important documents have been published in recent years, by both the Spanish Society for Palliative Care and the Catalan-Balearic Society for Palliative Care, including:

1) *Guide to Emotional Support for Patients at the End of Life and Their Loved Ones* (February 2010).[22] This document advocates providing emotional support and including psychological aspects in decision making, detecting the psychological complications resulting from these processes, and relieving the suffering of the patient and his or her loved ones.
2) *Care through Food*.[23] This document tackles end-of-life nutritional issues (for example, the chapter entitled *Asthenia, Nutrition and Anorexia in Cancer*), myths are debunked (if you don't eat you won't get well, you can't take the medicine on an empty stomach, etc.), nutritional recommendations are made (for example, taking part in choosing the menu will improve the patient's degree of control and self-esteem), and so on.
3) *Practical Guide for Handling Irruptive Pain in Cancer*.[24] This document lists advice, recommendations and treatments for relieving irruptive pain in cancer, defined as "a transitory exacerbation of pain that appears, either spontaneously or related to a predictable or unpredictable specific trigger, despite the existence of an adequately controlled stable basal pain".
4) *Guide to Music Therapy in Palliative Care*.[25] This document analyses the patient's involvement in musical and creative experiences, and to what extent they may have an impact on the improvement of his or her quality of life at this stage.

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[22] Societat Catalano-Balear de Cures Pal·liatives Acadèmia de Ciències Mèdiques i de la Salut de Catalunya i de Balears, at www.academia.cat/files/204-5908-FITXER/GuiaparalaatencionemocionalCast.pdf, last visited May 2018.

[23] Librán, A. (ed.), at www.academia.cat/files/204-5901-FITXER/ComoCuidarAlimentando2014.pdf.

[24] Garzón Rodríguez, C.; Farriols Danés, C.; Rovira Oliva, G.; Rodríguez Trujillo, M.; Porta i Sales, J., at www.academia.cat/files/204-5902-FITXER/GUIACas tellanov1.pdf.

[25] Alegre, A.; Bellver, I.; Del Campo, P.; Navarro, C.; Ripa de la Concepción, A.; Rodríguez, P., at https://es.scribd.com/document/360699786/Grupo-de-Trabajo-de-Musicoterapia-de-La-Sociedad-Espanola-de-Cuidados-Paliativos-MUSPAL, last visited, May 2018.

Lastly, the World Health Organization has appointed Xavier Gómez Batiste, the director of the Chair of Palliative Care at the University of Vic (Barcelona) and the person who introduced palliative care to Catalonia, for the purpose of organizing the palliative care programmes in this organization, taking into consideration not only clinical factors but also, in his own words, "dignity, spirituality and loneliness".[26]

10. Recommended reading

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Molero Martín-Salas, M. (2014). *La libertad de disponer de la propia vida desde la perspectiva constitucional*. Madrid: Centro de Estudios Políticos y Constitucionales.

Navarro Michel, M. (2007). "Médicos, familia y pacientes. Sobre las voluntades anticipadas", *Revista Jurídica de Catalunya*, no. 3, pp. 687-718.

Luna, F.; Van Delden, J. (2004). "Is Physician-Assisted Death Only for Developed Countries? Latin America as a Case Study", *Journal of Palliative Care*, vol. 20, no. 3, pp. 155-162.

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[26] MacPherson, A. *La Vanguardia*, 19 November 2014. Also, Gómez-Batiste, X.; Alentorn, A. P.; Espinosa, J.; Caja López, C. (2010). "Diseño, implementación y evaluación de programas públicos de cuidados paliativos." *Medicina clínica*, ISSN 0025-7753, vol. 135, no. 4, pp. 179-185; and Gómez-Batiste, X.; Nabal Vicuña, María; Trelis Navarro, J., et al. (2008). "Evaluación cualitativa del desarrollo del Proyecto Demostrativo OMS de Cuidados Paliativos de Cataluña a los quince años de su implantación y propuestas de mejora del programa". *Medicina paliativa*, ISSN 1134-248X, vol. 15, no. 5, pp. 293-300.

Puigpelat Martí, F. (2011). "Feminismo y las técnicas de reproducción asistida". *Bioética y Derechos Humanos* (Ana María Marcos del Cano, coord.), pp. 105-118.

Royes, A. (coord.) (2016). *Morir en libertad*. Universidad de Barcelona.

Singer, P. (1997). *Repensar la vida y la muerte. El derrumbe de la ética tradicional.* Buenos Aires: Paidós, pp. 67-87.

7

Transplants

1. INTRODUCTION[1]

The first bioethical conflicts in which the media coverage made a big impact on public opinion arose over heart transplants, since the possibility of replacing a patient's damaged heart with another healthy one from a deceased donor originated, apart from the natural scientific paradigm shift, a series of very important ethical and conceptual issues. Thus, questions such as human identity or the concept of death itself took on a new dimension thanks to the new technologies, generating an interesting debate that, over time, has been transformed into a state of opinion favourable to this kind of operation.

The reality is that progress in surgical techniques and immunosuppressive drugs have made it easy to perform a large number of transplants, with a reasonable level of success from the technical point of view, and this has contributed to them being widely accepted in society. Moreover, regulation of transplants has allowed them to become widespread and, consequently, in the context of safeguarding the right to health, the adoption of incentivizing criteria of solidarity and social wellbeing.

The two mainstays of the success of the Spanish model have been, on one hand, making every citizen a potential donor through the regulation of presumed consent (the deceased's organs can be removed and donated provided that they have not stated their opposition to it), with the requirement of altruism in donation (financial gain is prohibited, as the human body and its parts cannot be the source of profit). On the other hand, no less important, is the model of transplant coordination, according to which in every transplanting hospital — and also those that only perform organ removals — there are pro-

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[1] The precedent for this chapter was the chapter on bioethics and transplants in the book by CASADO, M. (comp.) (2007). *Nuevos materiales de bioética y derecho.* Mexico City: Fontamara; and *Principios éticos y nuevos problemas de los trasplantes. Manual de coordinación de trasplantes*. Barcelona: Transplant Procurement Management. Les Heures. University of Barcelona. Fundació Bosch i Gimpera, 2005, pp. 337-346.

fessionals specifically trained for this task, which includes the obtainment of the family's consent (assent). The Spanish transplant model goes hand in hand with a high level of financial investment and has highly motivated personnel whose competence is recognized, and therefore this model has been copied in many countries.

2. HISTORICAL AND LEGAL CONTEXT

Although we have become accustomed to the good acceptance that transplants enjoy in contemporary society, the reality is that, historically, not only has it been necessary to overcome technical obstacles, but moral ones as well.

Due to the prohibition, shared by Romans, Christians and Muslims (with honourable exceptions), on dissecting cadavers, for many centuries it was thought that the human body was similar to a pig's, because doctors such as Galen had used these animals for their research and had extrapolated the results to human beings. As recently as the 1950s, Pope Pius XII spoke in these terms about transplants, then incipient:

> To demonstrate that the extirpation of organs necessary for transplantation from one living being to another is in accordance with nature and legitimate, it is placed on the same level as that of a particular physical organ performed in the interest or for the benefit of a complete physical organism. The individual's limbs would here be thought of as members and parts of the total organism that is humanity, just as — or almost — they are part of a person's individual organism. The argument then goes that if it is permitted, in case of need, to sacrifice a particular part (hand, foot, eye, ear, kidney, sex gland) to the organism of man, it would be equally legitimate to sacrifice this particular part to the organism of humanity (in the person of one of its sick members). The end pursued by this line of argument, curing another's person's illness, or relieving it at least, is understandable and praiseworthy, but the method proposed and the proof on which it rests are erroneous.[2]

Religious taboos, irrationality, theological disquisitions, unjustified fears, and so on, have historically been obstacles as formidable as those inherent in discovering the secrets of nature, hence the huge difficulties that progress

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[2] Pius XII. Address to cornea donors. Unione Italiana dei Ciechi and Associazione Italiana de Medici Oculisti (14 May 1958), in DÍAZ MORENO, J. D. (1968). "Los trasplantes de corazón y su problemática moral". *Arbor*, April 1, no. 69, p. 268.

in fields such as biomedicine or biotechnology has faced, similar to those that cosmology faced in its day.

Now that religious prejudices have been overcome, it can be said that organ transplants are one of the bioethical problems that have been most promptly regulated in different countries.[3]

In the case of Spain, the law establishes a series of general principles that attempt to combine the freedom of the person and the right to one's own body with the altruistic act, with respect to society, that organ and tissue donation represents. The requirements demanded by law are the following:

1) The existence of a therapeutic end (although in the case of tissues — from a dead donor — teaching or research interest is also acceptable, as long as the ethical requirements for biomedical research are respected). In this sense, it may be said that the framework established by constitutional law for the safeguarding of health is in operation, which also includes the legally established presumption that every cadaver is a potential donor. Obviously the right to decide about one's own body exists, but it must be exercised while the person is still alive. When the person dies, if they have not made use of their right to arrange something else, the value of solidarity with society as a whole takes precedence (we should remember that, from a legal point of view, the cadaver would be considered a thing).[4]

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[3] In the case of Spain, the regulation of this issue is the now classic Law 30/1979, of 27 October, regulating the removal and transplantation of organs, which despite its age is still in force; Royal Decree 1723/2012, of 28 December, regulating the activities of obtainment, clinical use and territorial coordination of organs destined for transplantation, and establishing requisites of quality and safety; and Royal Decree 1825/2009, of 27 November, by which the Statute of the National Transplant Organization is approved. By the Council of Europe, that laid down in the European Convention on Human Rights in Biology and Medicine, especially chapters VI and VII and in the additional Protocol on the transplantation of organs and tissues of human origin, which completes it, both ratified by Spain. At European Union level, there is Directive 23/2004/EC, of the European Parliament and the Council, of 31 March, relative to the establishment of quality and safety regulations for the donation, obtainment, evaluation, processing, preservation, storage and distribution of human cells and tissues; Directive 2010/53/EU of the European Parliament and the Council, of 7 July 2010, on quality and safety regulations of human organs destined for transplantation; Implementation directive 2012/25/EU, of 9 October, with the information procedures for exchange between member states of human organs destined for transplantation; and Directive 2015/566/EU, of 8 April, which applies Directive 2004/23/EC with regard to procedures for verification of the equivalence of the quality and safety regulations of imported cells and tissues. Lastly, there is the Declaration of Istanbul on organ trafficking and transplant tourism, in which guidelines are established for avoidance of commercialization and financial discrimination in this matter.

[4] We could add that the additional Protocol on the transplantation of organ and tissues of human origin establishes that "tissues will be assigned only to patients appearing on an official waiting list, according

2) Confidentiality. The law establishes that information may not be disclosed that would make it possible to identify either donors or receivers. Publicity about donation for specific cases of people or clinics is therefore not authorized. Obviously, in the case of inter vivos donation, this requirement does not apply.

3) Gratuity. This issue arouses controversy in international forums, since it questions whether the European model of gratuity, established specifically in article 21 of the Convention on Bioethics, is exportable. The different socio-economic reality of some countries in the developing world poses the need to guarantee the existence of alternatives so that, in certain places, people are not obliged to resort to selling organs in order to financially ensure their survival and that of their family. The information we receive periodically about cases of organ trafficking (even by people condemned to death, as in the case of China) makes it clear, once again, that situations of extreme poverty and the lack of transparency encourage and provide cover for clandestine and iniquitous trafficking that we must all condemn.

This requirement poses specific problems when exchange exists between countries with very different legal and cultural systems. For this reason, the European Union passed Implementing Directive 2012/25/EU, of 9 October, with the information procedures for exchange between member countries of human organs for transplantation. In this respect, the Protocol to the Convention on Bioethics establishes that:

> In the case of international agreements about organ exchange, the procedures must also guarantee effective and justified distribution among all the participating countries, bearing in mind the principle of solidarity within each country.

Following this line of avoiding abuses or immoral practices in international contexts, article 15.1 of the Royal Decree of 2012 establishes that, in Spain, human organs for transplantation entering or leaving the country will be subject to prior authorization by the Ministry of Health, Social Services and Equality, through the National Transplant Organization.

The establishment of especially scrupulous requirements between the different countries has been completed with specific calls to the medical com-

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to transparent objective regulations, and duly justified as regards medical criteria" (Spain signed the said protocol through the Instrument of ratification of the additional Protocol to the Convention Relative to Human Rights and Biomedicine on the Transplantation of Organs and Tissues of Human Origin, signed in Strasbourg on 24 January 2002. BOE no. 25; Thursday 29 January 2015).

munity, due to the privileged position it occupies in this kind of operation. Thus, article 4 of the additional protocol on the transplantation of organs and tissues of human origin establishes the following:

> Article 4. *Professional obligations and rules of conduct and protocol*
> Any intervention in the field of the transplantation of organs or tissues must be made *respecting professional regulations and obligations, and the rules of conduct* applicable in this matter. [Our italics.]

The ultimate aim is to avoid the commercialization of organs. Thus, the Declaration of Istanbul supplies two important definitions that must be borne in mind:

> *Organ trafficking* is the obtainment, transportation, transfer, concealment or reception of persons living or dead or their organs by way of a threat, the use of force or other forms of coercion, kidnapping, fraud, deception or abuse of power or of a vulnerable position; the handing over or receipt of payments or profits by a third party to obtain the transfer of control over the potential donor, aimed at exploitation through the removal of organs for transplantation.
>
> *The commercialization of transplants* is a policy or practice in which an organ is treated as a commodity, including its purchase, sale or use to obtain material benefits.

However, the law has not put an end to the abuses that have direct or indirect repercussions on the issue of gratuity. Therefore, based on the fact that "the algorithms of organ allocation are very complex and include analytical data that can be manipulated", Chloë Ballesté tells how, in recent years, several cases of "fraudulent manipulation of analytical results by healthcare professionals for the purpose of giving patients an advantage and prioritizing their transplants" have been uncovered in Germany.[5]

And in Spain, in 2017 the Spanish Supreme Court confirmed a sentence by a provincial court in which two Spaniards were found guilty of paying a beggar from outside the EU to donate a kidney. The High Court ruled that an error of prohibition (not knowing that donation for money is prohibited) could not

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[5] Ballesté, C. "Donación y trasplante de órganos y tejidos: ¿altruismo o negocio?" In: Casado, M. (coord.). *De la solidaridad al mercado. El cuerpo humano y el comercio biotecnológico.* Barcelona: Edicions de la Universitat de Barcelona, p. 242.

be alleged for this type of case, which creates an important precedent for future cases.[6]

In sum, we must stress that the requirement for gratuity is rooted not only in the concept of dignity, but it is also based on the value of fundamental equality among human beings and on the principle of non-discrimination for reasons of money, sex, race, nationality, or any other kind. Moreover, the risks concerning the continuity of this requirement are coming faster and faster due to technological progress, which is making it possible to divide the human body up into countless parts (cells, organs, genes, etc.) that may be the object of direct or indirect commercialization,[7] or facilitating contact between interested parties without going through the proper channels (for example, through the creation of computer applications to put potential donors in contact with those in need of organs).

4) Education and publicity. Organ donation must always be encouraged generally, stressing especially its altruistic and voluntary nature. Indeed, our laws point specifically to the need for the healthcare authorities to promote the education of the population on these matters, since it has been proven that the role of education in this field is crucial; hence the culture of donation must be stimulated if it is really considered that benefits worthy of being fostered arise from it.[8] At the same time, the obligation of healthcare professionals to receive continuous training is emphasized in our legal system, a general obligation for these groups and which is even acknowledged ethically.

In conclusion, after 40 years of experience, a positive assessment can be made of the existing legal framework in Spain, as it has made it possible for the Spanish model to occupy a pioneering place in Europe and the world.

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[6] Supreme Court. Criminal Law section. Section 1. Sentence no. 710/2017, of 27 October. RJ 2017/4697.

[7] See, on this point, the abovementioned book by Casado, M. "Gratuidad o precio." In: Casado, M. (coord.) (2016). *De la solidaridad al mercado. El cuerpo humano y el comercio biotecnológico.* Mexico City: Fontamara, new edition by Edicions de la Universitat de Barcelona, 2017.

[8] On this point, the Protocol to the Convention Relative to Human Rights and Biomedicine on the Transplantation of Organs and Tissues of Human Origin states: "Considering that, taking into account the shortage of organs and tissues, suitable steps must be taken to increase donations of them, in particular by informing the public of the importance of organ and tissue transplants and through the promotion of cooperation in Europe in this field." Moreover, article 6 of the Royal Decree of 2012 establishes that: "2. Human organ donation will always be encouraged generally and its voluntary, altruistic and disinterested nature will be emphasized. 4. Publicity for organ donation for the benefit of specific people, healthcare centres, or institutions, foundations or particular companies is prohibited. Furthermore, deceptive publicity is expressly prohibited that is misleading about the obtainment and clinical use of human organs, according to available knowledge."

3. BIOETHICAL ASPECTS OF REMOVING ORGANS AND TISSUES FROM LIVING PERSONS

In Spain, the majority of the organs used for transplants come from cadavers. The success of our model has been based on the flexibility of the coordination of the detection and transplantation system and the proper management of waiting lists, taking into consideration obvious medical criteria. In this sense it may be said that the early inclusion in the law of brain death as a valid criterion for certifying death was crucial for the development of transplants, from not just the medical point of view, but the legal one too.

Indeed, the drafting of Royal Decree 2070/1999, of 30 December, regulating the activities and the obtainment and clinical use of human organs, and territorial coordination in matters of organ and tissue donation and transplantation, the precedent of the law currently in force, was due among other factors to the need to adapt the legal requirements to scientific progress. This meant, on one hand, accepting the new ways of determining death due to brain functions ceasing irreversibly, according to reliable medical criteria; and on the other, considering the need to also consider death as being due to the irreversible stoppage of cardiorespiratory functions, at the same time authorizing procedures to conserve organs so that they may be suitable later for transplants with guarantees of viability.

The greater need for organs, however, together with the reduction in donors arising from road accidents as a consequence of the many campaigns undertaken and safety measures adopted, has led to the boom in donation inter vivos, for which, moreover, better results are described. But must this possibility be encouraged? Might it be, to some extent, a form of emotional blackmail against the family? Organ donation for inter vivos transplants is authorized in Europe. The requirements are the following, taking into account both Spanish and European laws.

a) This kind of transplant is only admissible if a suitable organ or tissue cannot be obtained from a dead person and it is unfeasible to practise an alternative therapeutic method of comparable efficacy.

b) The transplant must have a therapeutic end (it is not accepted for scientific ends).

c) The organ removed must be used to substantially improve the life expectancy or conditions of the receiver.

d) Organs from living donors for subsequent transplantation may only be obtained in hospitals and clinics that are expressly authorized by the competent authority in the corresponding autonomous community.

e) Organs from a living donor may be removed in favour of a receiver with whom he or she has a close personal relationship. Nevertheless, the absence of such a close relationship is permitted, provided that the conditions of this donation are predefined legally and an independent authority approves it.

f) The removal of the organ must be compatible with the life of the donor and must not cause a serious reduction of their functional capacity. This entails that removal will only be legal in the case of pairs of organs (kidneys for example) and tissues that can be regenerated (for example, part of the liver).

g) Independent information must be offered to the donor about the risks involved in the operation.

h) Consent must be given freely, after previously receiving specific information, without generic clauses or presumptions, but with an ad hoc act of volition that must be very personal. Article 13 of the Protocol establishes that consent must be provided in writing, or, failing that, before an official authority. However, in the case of Spain, the procedure that must be followed is more strictly controlled, since article 8 of the Royal Decree of 2012 establishes that consent must be given before the judge in voluntary jurisdiction proceedings, after a favourable ruling by the ethics committee of the hospital or clinic where the operation will be performed. Both requirements signify an important additional guarantee.

In this respect, the conclusion reached in the first National Congress on Bioethics and Transplants, in Pamplona in November 2003, is interesting:

> The fundamental objective of the committee, in this kind of report, is to be the donor's guarantor and to endeavour to ensure, as far as is possible, that his or her decision is genuinely autonomous, that is, voluntary, free and suitably informed and understood.[9]

A point of reference for assessing the level of suitability of this kind of transplant is medical ethics:

> Organs must not be removed if this shortens the donor's life expectancy, nor can the operation go ahead if the potential damage for the donor exceeds the

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[9] Martínez Urionabarrenetxea, K. "Consideraciones éticas del trasplante de donante vivo". *Trasplantament.* Organització Catalana de Trasplantaments. Servei Català de la Salut. Societat Catalana de Trasplantament, pp. 10-13.

> benefits for the receiver, which rules out the use of single organs, or of an organ when what is left is insufficient or there is a risk of it being so.[10]

Lastly, we should point out the following rigorous and profound reflections on this issue:

> Juan Luis Trueba, head of the Neurology department and former chairman of the Ethics Committee of Doce de Octubre Hospital, said he was convinced that only the practical recognition of the coherent altruistic criterion of donors leads to the conviction that living-donor transplants must continue to be performed “despite the confirmation that the physical damage of both outweighs the physical benefit of the receiver”, he stated. “This practice, exceptional with respect to the principle of nonmaleficence, is extremely hard to manage and cannot be decided by the team of surgeons alone; but it must not be restricted”, Trueba claimed. “Because we must consider damage not just as something physical or objective, but in relation to the values of the patient, gauging the moral or other type of satisfaction that the decision generates in the donor. In short, taking into account the patient’s scale of values and respecting the criteria of legality.”[11]

i) Article 13 of the Protocol to the European Convention on Bioethics establishes that the donor may withdraw their consent at any time before the operation. In the case of Spain, the legislation guarantees this possibility even more by requiring a period of at least 24 hours between the granting of consent and the transplant. In addition, it establishes that refusal to continue with the transplant does not under any circumstances make them obliged to pay compensation, a measure that for example is not specifically included in this protocol.

j) Article 14 of the Protocol to the European Convention on Bioethics establishes specific requirements for the case of persons who lack the capacity to give consent. Thus, this type of donation must be exceptional and only for the removal of regenerable tissues (the donation of a kidney, for example, would be excluded). Further requirements are that the receiver must be a brother or sister; that the donation could save their life; that the donor

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[10] Quevedo Guanche, L. *Consideraciones éticas en el trasplante hepático con donante vivo relacionado. Hospital Clínico Quirúrgico Hnos. Ameijeiras*, at www.sld.cu/galerias/pdf/uvs/cirured/etica_trasplante.pdf

[11] Muez, M. (2003). “Difícil balance entre riesgo y beneficio en los trasplantes de hígado de donante vivo”. *El País*, 2 December 2003.

> does not express their refusal to do it; and that consent be granted by a representative of the donor or, failing that, the competent authority. These requirements are only relaxed if the donation affects cells, in which case neither the receiver has to be a sibling, nor does it have to be a matter of life and death. The extraction of these cells must cause minimal risk and discomfort.
>
> Nevertheless, for the case of Spain article 8 of the Royal Decree of 2012 restricts this kind of donation even more, since it establishes that the organ donor must not suffer from or present mental deficiencies, mental illness or any other condition due to which they are unable to give their consent in the way indicated. In addition, the obtainment of organs from minors is expressly excluded, even with the consent of their parents or guardians.

In 2011 the University of Barcelona's Bioethics and Law Observatory Opinion Group published a document on living donor organ transplantation in which it recommended: *a*) considering this kind of transplant as subsidiary to cadaver transplantation, with the aim of avoiding illegal organ trafficking; *b*) avoiding gender bias, due to the fact that the percentage of living donors is greater in women than in men, and *c*) taking specific steps to guarantee informed consent in this kind of donation, avoiding extreme situations that unduly pressurize donors.[12]

4. ISSUES FOR DEBATE: PRESUMED CONSENT AND BRAIN DEATH

Science and the law are advancing at different rates because, among other factors, the pace of scientific discoveries and their practical application is currently accelerating, something especially obvious when it comes to creating rules for biotechnologies. Indeed, it is often pointed out that the very short time between discovery and application is one of the main reasons why the debate is so complicated, along with society's lack of assimilation and reflection with respect to science and technology. This is the case with the determination of consent or with the criterion of death that it is decided to establish and the problems resulting from it.

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[12] *Document on Transplantation from Living Donors*. Bioethics and Law Observatory, University of Barcelona. Coordinated by L. Busian, R. García Manrique, M. Mautone and M. Navarro (2011), at http://hdl.handle.net/2445/104602.

4.1. Consent, presumed or express

With regard to the determination of a dead person's consent in organ donation for transplantation, there are two systems in comparative law: *a*) the presumption of this consent, unless expressly stated to the contrary, and *b*) the need to specifically formulate consent personally or through the family in the case of death, as its granting is not presupposed.

A paradigmatic example of the first option is Spanish legislation; and an example of the second system, which does not presume the deceased's consent for the removal of organs and their subsequent donation, is the Chilean legal system. In other countries in the region, too, the issue has been fiercely debated due to an underlying fear of being declared donors without the sufficient guarantees that everything possible has been done to save the life of someone who it was believed was about to die.

4.2. The criterion of brain death

The second issue that arouses profound reflection is the decision to adopt the criterion of brain death. This has in general been widespread in Europe and it has medical, ethical and legal agreement. It is interesting to mention the thoughts of the philosopher Peter Singer with regard to the way this criterion of death is regarded in our culture and the consequences of its medical and legal adoption.

In his book *Rethinking Life and Death* Singer draws attention to the changes implied in taking such a definition to its logical conclusion with regard to the protection of goods and interests, pointing out that, precisely, ethics deals with making decisions about the right way to live life, which also includes death. Choosing brain death as a yardstick involves stressing its association with the idea of consciousness, of personality, presenting many advantages for future transplant patients, without, on the other hand, harming anyone.

The option taken in Spain by Royal Decree 2070/1999, of 30 December, and later by Royal Decree 1723/2012, leaves the decision of what evidence makes it possible to reliably determine a person's death in the hands of the doctors, since this is a diagnosis that only specially qualified personnel can make. Article 9 of the Royal Decree of 2012 regulates this issue, together with the criterion of cardiorespiratory arrest, in the following way:

> 2. Organs may only be obtained from deceased persons after diagnosis and certification of death performed in accordance with what is laid down in this royal decree and particularly in Appendix I, ethical requirements, scientific progress in the matter and generally accepted medical practice: […] The individual's death may be certified after confirmation of the irreversible cessation of circulatory and respiratory functions, or irreversible cessation of brain functions. 3. Irreversible cessation of circulatory and respiratory functions will be acknowledged through an appropriate clinical examination after a suitable period of observation […] 4. Irreversible cessation of brain functions, i.e., the confirmation of brain death for which the structural aetiology is known and irreversible in nature, will be acknowledged through a suitable clinical examination after an appropriate period of observation.

These are delicately balanced situations in which we must unavoidably make decisions. By choosing one position — even though it may be abstention — one is also choosing an initiative, not just clinical but moral and legal. It is obvious that in Spain transplant legislation has followed correct patterns of legislative technique and, from its agreed drafting to its application by the judiciary, it is a model of consideration and of the public authorities' involvement in an undoubtedly social task. But legal regulation does not end the social debate and aspects still remain that deserve to be discussed and dealt with.

5. XENOTRANSPLANTS

The scarcity of organs has forced researchers to ask themselves to what extent the organs, tissues and cells of animals may be compatible with human beings. Nevertheless, this option raises many objections, both ethical and in reference to the safety of our species. We point out the following characteristics of this issue:

a) Normalized use. Several products of animal origin are now frequently in use in medicine, such as insulin or conjunctive tissues; however, various difficulties arise depending on whether they are organs such as the heart — to which greater symbolic importance is attached — or living tissues, which may give rise to problems to which science has yet to find an answer.

b) Rejection. An important problem that must be considered is the rejection of the transplanted organs. Although it may be said that in recent years progress has been made in the control of the phenomena of rejection and compatibility, there are still obscure areas, including from the psychological point of view.

c) Transmission of viruses. It is also necessary to take into consideration the risks involved with xenotransplants, not just from the point of view of the subject who takes the decision to have one, but for the society in which they live, as this kind of transplant may cause viruses and retroviruses to break through the barriers between different species and mutate unpredictably. The assumption or not of this kind of scenario overrides any personal decision, hence individual risks and benefits, on one hand, and those assumed by the group, on the other, must be assessed. In our opinion, the subject's mere consent cannot be a good enough guarantee, as it must be weighed up by the community as a whole, and by the relevant public authorities.

d) Choice of species. Even supposing that it is legitimate to agree to the use of animals to save human lives, problems also arise when choosing the animal species from which the organs must be taken. The use of primates was initially proposed, due to their greater proximity to humans, but these days it is considered preferable to use pigs, due to their habitual consumption and the ease of breeding them. Primates, besides being protected species, cause greater moral unease, precisely because of their proximity to our species.

e) Financial aspect. Xenotransplants are an important potential market for the major biotechnological and pharmaceutical companies, whereby there is a risk of purely financial criteria prevailing where up to now the principle of gratuity has been consolidated. It is also true that, on the other hand, it could be argued that the spread of xenotransplants might make it possible to put an end to organ trafficking.

f) The initial stages of the use of xenotransplants in human beings are particularly difficult, firstly when carrying out the first clinical trials and deciding who will be the most suitable patients for them, and then due to the need to establish epidemiological controls and rules to be followed by the healthcare authorities. Besides the need to establish rigorous criteria for inclusions in the lists, it is also necessary to put in place clear procedures to ensure that the information patients receive is exhaustive and that the consent they give is truly informed and free. Competent specialists are needed for this, bearing in mind that prolonged isolation measures may be necessary and that false hopes must not be raised.

g) Genome editing. Parallel to these debates, important progress is taking place in genome editing, paving the way for the widespread use of xenotransplants. Techniques such as CRISPR, which make it possible to activate or silence genes, or to transfer genes from one species to another very easily and cheaply, will in the not too distant future make it possible to prevent the organs from different animal species, pigs especially, from transferring viruses to humans, hence the hopes placed in this technique.

h) The law. In neither Spain nor the European Union are xenotransplants specifically prohibited. Another matter is the precaution with regard to this issue. In this respect, the Ruling of the European Economic and Social Committee on the proposed directive of the European Parliament and the Council relative to the establishment of quality and safety regulations for the donation, obtainment, verification, processing, storage and distribution of human cells and tissues (COM, 2002, 310, 2002/0128 COD) proposed to exclude from the scope of this regulation the organs, tissues and cells used in xenotransplants, due to the fact that "a great deal of research still remains to be done". Following this proposal, Directive 23/2004/EC, of the European Parliament and the Council, of 31 March 2004, relative to the establishment of quality and safety regulations for the donation, obtainment, verification, processing, storage and distribution of human cells and tissues, excluded organs, tissues and cells of animal origin from the scope of application. And Royal Decree 1723/2012, of 28 December, which regulates the activities of obtainment, clinical use and territorial coordination of organs destined for transplantation and the establishment of quality and safety requisites, also excluded xenotransplants from its regulation.

i) Moratorium. In 1999, the Parliamentary Assembly of the Council of Europe issued a resolution in which, protected by the principle of precaution, it called for a legally binding moratorium for xenotransplantation to be decreed, due to the risks it generates for humans.[13] However, this proposal received a lukewarm response in the scientific community, the predominant opinion being that it was better to continue with research, maximizing precautions of course, but in any case without halting progress. The Committee of Ministers of the Council of Europe limited itself to creating a working party that concluded its meetings with a document entitled "The situation in the field of xenotransplantation",[14] the step prior to the

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[13] Recommendation 1399/1999, on Xenotransplantation. Parliamentary Assembly of the Council of Europe (29 January 1999).

[14] European Commission. Health & Consumer Protection Directorate General. Opinion on the state of the art concerning xenotransplantation. Adopted by Scientific Committee on Medicinal Products and Medical Devices (1 October 2001), at http://ec.europa.eu/health/ph_risk/committees/scmp/documents/out38_en.pdf.

publication of *Recommendation 10/2003, on Xenotransplantation*,[15] in which, contravening the Parliamentary Assembly, it did not propose a moratorium, but specific precautionary measures for this kind of transplant.

In conclusion, everything that has so far been mentioned clearly shows that there is a need for specific national and international regulations to establish a harmonized framework of certainty and safety. The different legal systems must ensure that caution prevails in a field in which the potential dangers are not properly controlled and where there is the need for more in-depth preclinical research before taking the step of agreeing to clinical trials with human beings. This is a good place to turn to the oft-mentioned principle of precaution and to invoke the need to maximize responsibility when weighing up risks and benefits.

6. Recommended reading

Ballesté, C. (2016). “Donación y trasplante de órganos y tejidos: ¿altruismo o negocio?” In: Casado, M. (coord.). *De la solidaridad al mercado. El cuerpo humano y el comercio biotecnológico*. Mexico City: Fontamara (new edition Edicions de la Universitat de Barcelona, 2017).

Buisan, L.; García Manrique, R.; Mautone, M.; Navarro, M. (2011). *Document on organ transplants and live donors*. Bioethics and Law Observatory. Barcelona: Edicions de la Universitat de Barcelona.

Casado, M. (2007). *Nuevos materiales de bioética y derecho.* Mexico City: Fontamara.

— (2007). “Ethical and legal aspects of regulations governing transplants.” In: *Transplant Coordination Manual*, pp. 329 340. TPM.

Casado, M.; Lecuona, I. de; Navarro-Michel, M.; Royes, A.; Páez, G. (2014). “Bioethical and legal issues in tissue and organ donation of human origin for transplantation”. In: *Transplant Coordination Manual*, pp. 469-501. TPM.

Navarro Michel, M. (2017): “Menores de edad en el ámbito sanitario. Especial referencia al rechazo a las vacunas.” *Derecho de Familia. Revista interdisciplinaria de doctrina y jurisprudencia*. Argentina, no. 79, pp. 293-305.

— (2011): “Institutional Organisation and Transplanting the ‘Spanish Model’.” *Organ Shortage: Ethics, Law and Pragmatism*, A. M. Farrell, D. Price, M. Quigley (coords.). Cambridge: Cambridge University, pp. 151-170.

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[15] Council of Europe. Committee of Ministers. Recommendation. Rec 2003/10 of the Committee of Ministers to member states on xenotransplantation. Adopted by the Committee of Ministers on 19 June 2003, at the 844th meeting of the Ministers’ Deputies, at https://rm.coe.int/16805df8df.

8 Bioethics and Environmentalism

1. INTRODUCTION[1]

Multiple theories and ideas converge in environmentalism. They include religious premises, condensed in the dichotomy between monotheism and pantheism; alternatives to the present economic model, reflected in the dichotomy between capitalism and socialism; theories about the moral and ontological status of non-human living beings; reflections on our long-term survival; needs in biomedicine and biotechnology; psychological projections about "Mother Nature"; climate change; mythical narratives about an idealized past; inescapable realities of the present; future dystopias, and many other things.

In this chapter we shall analyse some factors related to environmentalism, for instance the degree of contemporary overlap between bioethics and environmentalism; the existence of environmentalist statements in every meta-narrative intended to serve as an existential guide to human beings; our historical relationship with the planet, of which we are a part; the relationship between science and technology and the planet; our expectations about life, in both the short and the long term; our dependence, inescapable for now, on animals in biomedicine, and the degree of unnecessary cruelty that our species inflicts on animals.

After reflecting briefly on these issues, we shall propose a model for analysing the narratives about environmentalism using two variables, anthropocentrism and biocentrism. The resulting four models will enable us to fit in paradigms as diverse as Judaeo-Christianity, Marxism, the animal rights movement and ecofeminism.

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[1] This chapter is an adaptation of the paper on bioethics and environmentalism, written by Manuel Jesús López Baroni, and it forms part of the teaching materials for the University of Barcelona's master's degree in Bioethics and Law. www.bioeticayderecho.ub.edu/master.

2. PRIOR ISSUES

When analysing environmentalism it is necessary to take into account several superimposed thematic lines, hence we shall try to separate them in order to get a broader perspective. We shall comment briefly on the following issues:

2.1. Environmentalism in the early days of bioethics

As we have already mentioned, in the early days of bioethics there was a bitter debate about what subject should predominate in our discipline: environmentalism (the case of Potter, with reminiscences of Jahr) or clinical ethics (the case of the Jesuits of Georgetown). This theoretical debate, which was initially won by the Jesuits, is now clearly out of date due to the rapid development of biotechnology.

The possibility of modifying ad hoc the genetic makeup of living beings confers upon us a power different to that which the human race has historically had. The mechanisms of selection and crossbreeding, which for millennia produced certain animals (for example, dogs and cows) and food (maize, wheat, rice) have given way to a new, more substantial, global, and occasionally disheartening form of intervention in nature.

For this reason, although ecological concerns predate the development of bioethics, we may maintain that for different reasons, among them the acceleration of technology, they have in the end converged. Developing human organs in pigs to be transplanted, modifying insects genetically so that they can propagate and replace the already existing ones, creating human brain organules in rats to study our mental illnesses, gestating new life forms through synthetic biology, and so on, are lines of research that show us a high degree of overlap between animals, plants, the ecosystem, biomedicine, ethics and environmentalism. Not to mention the political, social and economic implications of these issues, against a backdrop of global warming. If it was once considered that environmentalism and bioethics were two separate disciplines, there can now be no doubt about how interrelated they are.

2.2. Environmentalism in the great metanarratives

Every worldview that aspires to make sense of or govern human beings contains axioms about what our relationship with all other living beings and even the ecosystem should be. From this postulate we see that instead of trying to define what environmentalism is, we should rather be examining the attitudes of different ideologies — religions included — towards the environment; that is, how these paradigms explain, justify and provide rationale for human beings' position of hierarchy or equality with regard to all other living beings, how legitimate their use is, what level of replacement and expansion we accept from the other species, and so on.

These differences between some worldviews and others are why we can talk of environmentalist attitudes. And, at the same time, maintain that there is no such thing as pure, strictly ecological environmentalism, which is only concerned about the ecosystem or non-human living beings, since the response to our relationship with our immediate surroundings is part of a larger series of statements that tell us which political model is better, what the relationship between human beings, peoples, cultures, should be like, what moral codes are acceptable, and an endless list of variables about communal living.

Metanarratives are all-encompassing explanations or justifications (worldviews, *Weltanschauung*, systems, etc.). Every metanarrative that aspires to dominate the human mind starts with an explanation of who we are and how we have reached this point. And our relationship with the world around us is part of this narrative.

This tells us, for example, that worldviews as different as Catholicism and Marxism have positioned themselves with regard to environmentalism. Their respective axioms (God exists, class division is the driver of society) make their environmentalist postulates coherent, which moreover discredit one another (the other is not a true environmentalist). Given that we do not have a metaphysical referee to decide who is more environmentalist than who, the result is a confused mixture of ideas, postulates and proposals that become more complex as we include more factors of analysis.

2.3. Religions and economics

One of the many classifications that can be made of religions distinguishes between monotheistic systems (Judaism, Christianity, Islam) and pantheistic ones, whose variability, in turn, exceeds the space we are able to devote to them here. With regard to our subject, we can claim that, with the logical qualifications, monotheistic religions are based on the premise that everything we see and touch has been created by their respective god and is at the service of the human race.

On the contrary, not only would pantheistic religions place humans on an equal footing with nature, they also sacralise it, attributing to it spiritual, miraculous qualities. Obviously, in this second group human beings' de facto power over nature would be more limited, so even more than in monotheism a large number of taboos, myths and prohibitions would restrict the acts that are legal when interfering in nature.

We can understand the way in which religion is able to condition, by placing ourselves at the extremes. The Calvinism that Weber described maintains that God has already decided who is going to Heaven and who to Hell.[2] But as we do not know, we can only sense our future in the afterlife through signs. Thus, if life is good for us on Earth (success in business, in politics, with friends), it is a sign that we are on the side of the chosen ones. Neoliberal capitalism would be a collateral effect of these presuppositions, and with them, any idea of respect, not just for the environment or animals, but for all other human beings, is pointless.

Thus, a religious worldview that promotes harmonious coexistence with its surroundings will depend completely on gathering food (we are going to suppose that not only would they not hunt, they would not use domestic animals either because it would be another way of objectifying nature). With a worldview such as this, certain levels of welfare would never be surpassed (there are many urban legends about hunter-gatherers' quality of life. If on top of that they are forbidden to hunt for moral reasons, the legend achieves the status of a children's fable).

The archetypal rapacious predatory neoliberal will always be able to say that thanks to the technological advances inherent in unbridled capitalism, some day we will cease to use animals as a source of nutrition or to test drugs (he is working to make the future of the human race ecological). On the contrary, a mystic and contemplative pantheist will always maintain that we only need plants to feed ourselves and that the Earth would be better off without us. The former will have it thrown in his face that we may end up destroying the planet through his intensive exploitation; the latter, that without science and technology we will be the ones that go extinct. Between both extremes there would be numerous narratives, with their contradictions, no matter how eclectic they are.

Norway, for example, is the dream of anyone who aspires to live in a social state. Its level of wellbeing, quality of life and respect for nature is the envy of

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[2] Weber, M. (2003). *La ética protestante y el espíritu del capitalismo.* Mexico City: Fondo de Cultura Económica.

all Europe. One thing is usually overlooked, however. The largest investment fund in the world (sovereign fund, in technical language; vulture fund in popular language) is the Norwegian, which is funded with the resources from the extraction of a gigantic oilfield inside its territory.

In other words, the model we all aspire to is financed by lending money to countries with financial problems, countries whose public debt has spun out of control and which as a side effect generates cuts in healthcare, education, and so on (we only have to think of Greece, Portugal or Spain). Thus, the largest investment fund in the world finances one of the best systems of social protection in Europe, but it does so at the expense of extracting finite natural resources, such as oil, which is essential in highly industrialized (i.e. polluting) societies, and moreover it lends money at the highest possible rate of interest to countries in debt, according to a Calvinist logic that is universally reviled when others do it but not when we do.

In short, if we correlate the two groups of religions mentioned, monotheism and pantheism, with a third subject, economics, we can understand some issues related to environmentalism. Thus, a narrative that promotes the sacralisation of nature will be more spiritual, respectful and environmentalist than one that does not promote it, of course, but it will also have less technological and scientific development. And on the other hand, capitalism, the industrial and technological revolutions, scientific and economic development, are the consequence of narratives (liberalism, Judaeo-Christianity, Marxism even, although from another economic perspective) that subordinate everything around us to our vital and intellectual needs, such as simple human curiosity, for instance.

When it comes to maintaining an environmentalist discourse, one must choose. It is essential to explain and justify how we should function on a planetary scale, since upholding local environmentalism at the expense of bleeding other countries dry, economically speaking, is as contradictory as defending planetary environmentalism at the expense of local scientific and technological progress.

2.4. The use of animals

Non-human living beings are so different from one another that it is frankly difficult to find generic rules that unify, for example, insects, species in danger of extinction, species that interact damagingly with the environment and endanger other species, mammals, and so on. The Australians' desperate efforts to exterminate millions of rabbits whose uncontrolled reproduction in their country threatens the habitats of other species (they have even used bacteriological weapons) are a good example of our contradictions.

The great apes represent our perplexity like no other group. Their genetic proximity to us has been the justification for attempting to grant them rights comparable to human rights (for example, the Great Ape Project). Critics say that rights can hardly be granted to those who have no responsibilities (and yet we give them to children), but, even so, a line of thinking has emerged that raises the status of the great apes with respect to all other living beings with the aim of banning experimentation with them or keeping them in non-natural habitats.

It was at this juncture where the expression "sentient beings" appeared, that is, non-human living beings that have feelings, on which the intention is to confer superior status.

Sentient being status has to face the inescapable fact that at the present time using animals to test drugs before they are given to humans is essential. No computerized model can replace the empirical verification of the effects on animals. This does not mean that it is not legitimate to aspire to replace them, but nothing points to it being possible in the medium term. In fact one of the paradoxes of the most modern technology, for now at least, is that not only is it not reducing our dependence on animal models but it is increasing it. Thus, for example, it is unthinkable to apply genome editing techniques, such as CRISPR, to human beings without first having experimented with them on animals close to us. And if human organs were successfully created in pigs, with the aim of transplanting them later, or even in the great apes, it would be such a significant advance for our expectancy and quality of life that we could hardly renounce it.

This reality check leads us to maintain that the most we can do is restrict the use of animals (for example, only when it is essential) and to mitigate their suffering as far as possible.

Of course, there are narratives that advocate eliminating ipso facto this use of animals, but there are important contradictions. Directly or indirectly, consciously or unconsciously, the members of the human race benefit, and will continue to benefit, from the use of animals. "Don't see, don't ask, don't want to know" is a legitimate option as long as it is consistent (for example, renouncing any human service or product, medicine included, where animals have previously been used).

2.5. The anthropological scale as an erroneous scale

When analysing our relationship with the ecosystem and all other living beings it is interesting to use non-human, i.e. geological, timescales.

Thus, in the last 100 years we have discovered that: *a*) there have been five great extinctions of living beings in the world; *b*) there are cosmological events (falling meteorites, supernova explosions, gamma rays) that would devastate life on our planet without us being able to do anything about it, and *c*) it is reasonable to infer that sooner or later the human race will face an event of this kind (for example, although millions of years from now, the sun will definitely become a red giant and will swallow up the Earth. For anyone who wants to see what a falling meteorite would mean, look for information on internet about the one that crashed into Jupiter in July 2009, and imagine the effects if it happened on Earth).

What place does science and technology have in this context, which is often overlooked because it belongs to another kind of worry? It seems obvious that contemplative mysticism would condemn us to the randomness of events. Only luck would prolong our existence.

At the other extreme are the so-called disruptive technologies (synthetic biology, biotechnology, nanotechnology, artificial intelligence, and so on), on to which we project our hopes of salvation in the long run (for example, in the seemingly distant future we aspire to leave our planet, taking with us as many living beings as we can). With disruptive technologies we are also going to need luck, of a different kind of course, but luck all the same. The possibility of us losing control of these technologies would condemn us long before nature itself does so.

This is the perspective from which we must view global warming. It is often forgotten that climate change has been a constant feature of the history of our planet (the Earth as a snowball is an extreme case of cooling, but there have been other periods with a higher average temperature than now) and its causes are not easy to understand, from volcanoes to the movement of the solar system around the galaxy (almost no one knows either that we complete a lap of the galaxy every 250 million years, and that our own galaxy spins around a black hole at a rotational speed of nearly one million kilometres an hour). We can only think about the stability of the climate, or even of the Earth, from ignorance.

The problem of climate change does not lie in change in itself, but in its causes: we — our species — are causing it, and in an extraordinarily short period of time. Although some scientists dispute the existence of the Anthropocene (our epoch is the Holocene, a period that began about 10,000 years ago and which is characterized by stable warm temperatures), no scientist disputes the gradual warming of the planet due to our industrial activity (deniers are to climate change what creationists are to biology. In fact, Conservapedia[3] devotes an article to the climate change "conspiracy", similar to the fossils conspiracy).

What conclusions can we draw from the reality in which we live? Basically, that if we do nothing we will become extinct; and if we go too quickly, as well. The truth is that Mother Nature lacks objectives, ends or an ultimate purpose, and this is why it is so dangerous to idealize it. Of the five species of hominids that existed when we appeared, we are the only ones left. If we cast our gaze back, or around us, we can only observe the constant disappearance of species, the victims of circumstances that they were unable to control.

We must place reflection on our relationship with all other living beings and how to preserve the planet for future generations between these two extremes, contemplating or accelerating.

2.6. Human stupidity

We cannot think about environmentalism without all our collective "skills" coming to the surface. The dodo, a type of flightless bird (hence it was initially called *Didus ineptus*),[4] represents the best possible example of this issue. Cut off with the fauna of Madagascar, it never encountered a human being until the sixteenth century, and so it did not run away from us. We know that it existed from the drawings left by colonists. According to legend the last one was beaten to death for fun. Even Schopenhauer had a theory about its lack of adaptation for survival.

Human stupidity is a variable that must be taken into account. On one hand, it is true that nature is sacralised, and protective, magical, shamanic and spiritual properties are attributed to it, sometimes putting environmentalism in the same bag as esoterica, but on the other hand human beings justify unnecessary animal suffering using big words (culture, folklore, tradition, etc.). Many towns and villages in Spain preserve traditions (pulling at the body of a

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[3] It is an encyclopaedia created by American neoconservatives because they consider Wikipedia to be too liberal. It is illustrative to read its articles on creationism, global warming, etc. At https://es.wikipedia.org/wiki/Conservapedia.

[4] Shapiro, B.; Sibthorpe, D.; Rambaut, A., et al. (2002). "Flight of the Dodo." *Science,* 1 March, p. 1683.

hen hanging by the neck, throwing animals off the church bell tower, setting fire to a bull's horns) that can only be described as stupid. Only recently have we begun to reflect on our barbarity.

Stupidity also functions on a planetary scale. We have thousands of nuclear bombs designed to eliminate all signs of life. The first time a nuclear explosion was tested it was thought that it might cause the whole of the Earth's atmosphere to ignite, but that did not stop it being tested. Radioactive fallout, carbon emissions, the emergence of leaders at the limits of normality, competition between blocks of countries for finite natural resources, the fragility of life, cosmologically speaking, are all factors that ultimately interact with human stupidity, with unpredictable results.

3. The narratives of environmentalism

Bearing in mind the many issues that must be taken into account when linking bioethics to environmentalism, we are briefly going to analyse the narratives that we can find in forms of environmentalism. For this, we shall use two variables, anthropocentrism and biocentrism, with two true values (represented by the numbers 1 or 0), and this produces a total of four possible combinations. We shall analyse them very succinctly, as it will enable us to fit in other issues related to this one.

3.1. "Anthropocentrism (1)" – "biocentrism (0)"

In this first combination, human beings are at the top of the hierarchy, so that all the living beings around us would be at our service. The only limit would be not to mistreat other living beings unnecessarily, as we would be guilty of unjustified depredation. It would be the model typical of Judaeo-Christianity, of the European enlightened liberal tradition, and of Marxism too.

For Judaeo-Christianity the world and everything in it has been created by God, but there is an ontological gradation. The human being is on top, and all other living beings and inert matter are at our service ("And God said, let us make mankind in our image … to rule over the animals", Genesis, 1:26; "so that with the subjection of all things to man the name of God may be admired in the world", Vatican Council II). Jesús Mosterín reminds us that Saint Augustine made the transition from a love of animals and plants, typical of vegetarian Manichaeism, to Christian anthropocentrism: "Christ himself showed that refraining from killing animals and destroying plants is the height of superstition" (Saint Augustine, in Mosterín,[5] 2014:55). This tradition was continued by Saint Thomas in the Middle Ages: "Hereby is refuted the error of those who claim it is sinful for a man to kill dumb animals […] He that kills another's ox, sins, not through killing the ox, but through injuring another man in his property."[6] And, in the Enlightenment, Kant says, "that he [in reference to human beings] constitutes in reality the natural end, and nothing of that which lives on the earth could compete with him in this sense".[7]

This simple scheme permits the exploitation of all other living beings, ecosystems and all the resources we can extract from the environment. And, ultimately, capitalism.

However, Christian anthropocentrism has two limits: *a*) depredation is prohibited, that is, the unjustified destruction of all other living beings and ecosystems, and *b*) the sacralisation of nature is prohibited. In other words, nature has been created by God, but it is not in itself God. Hence, the *Compendium of the Social Doctrine of the Catholic Church* repudiates ecocentrism and biocentrism, without in doing so ceasing to consider itself environmentalist ("The Magisterium stresses the responsibility of humans to preserve a whole and healthy environment for all.").[8] The first encyclical by the present pope, Francis, talks precisely about environmentalism, but stays within the limits mentioned.[9]

The paradigm of European enlightened/liberal modernity, even when it demystifies the justification of our position in the pyramid, includes that same model in its relationship with all other living beings. Human beings are at the top. And all the other living entities remain at our service. The development of capitalism in the last 200 years, via the industrial and technological revolutions, has only been possible through the use of a worldview that makes the intensive exploitation of natural resources possible (which has not prevented some enlightened souls from showing themselves to be more respectful of animals than their contemporaries).

Lastly, Marxism also corresponds to this Judaeo-Christian model mediated by Eurocentric liberal enlightenment. The unit of interest of Communism is

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[5] Mosterín, J. (2014). *El triunfo de la compasión. Nuestra relación con los otros animales*. Alianza Editorial, pp. 55-56.

[6] Ibid.

[7] Ibid.

[8] Catholic Church, *op. cit.*, *Compendio de la doctrina social de la Iglesia católica*, pp. 131-132.

[9] Francis (2015). *On Care for our Common Home.* Encyclical letter.

the working class, as the convertible human being is in Christianity and the bourgeois in the enlightened liberal model. And our entire environment, ecosystems and living beings included, is subordinated to the interests of the proletariat. The Marxist pyramid of interest is the same as the Christian and liberal ones, for all that its theoretical presuppositions (materialism) are different. Indeed, it is interesting to compare Soviet and western constitutionalism: before the Constitution of 1977 the obligation to preserve nature was not mentioned in the USSR, an obligation that would be remembered by Gorbachev in his speech to the Supreme Soviet in 1988, just before the final collapse of the Communist bloc,[10] conditioned by the nuclear accident at Chernobyl two years earlier. Something similar occurs with Cuban constitutions.

The conclusion is obvious: concern in the Communist world for the rights of animals or the protection of ecosystems has been historically non-existent. And when they began to think about this issue, they copied the articles from Western liberal constitutions that established generic obligations related to the duty to preserve nature.

We can contrast the model that we are examining with one of the issues of biotechnology and environmentalism that has received most coverage in the media: genetically modified organisms (GMOs). The *Compendium of the Social Doctrine of the Catholic Church* authorizes intervention in the genetic makeup of non-human living beings. The recent encyclical by Pope Francis even establishes analogies between what our ancestors did, through the selection and crossbreeding of species, and modern genetic engineering.

Similarly, there is no classic Marxist text from which the conclusion can be drawn that modifying the genetic makeup of living beings is, for example, a bourgeois heresy. On the contrary, and in the light of its constitutionalism, we may be certain that if the Soviet Union had had the right technology, it would also have competed with the United States of America in genetically modified organisms.

Pope Francis alerted people in the encyclical to the social and economic effects of GMOs: the concentration of land in the hands of a few people, the disappearance of small producers, the migration of farmers upon not being able to compete with companies producing GMOs, oligopoly and the denunciation of (sterile) "terminator" seeds because they generate the farmer's contractual dependence, and so on.

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[10] Mikhail Gorbachev, report submitted in the twelfth extraordinary period of sessions of the Supreme Soviet of the USSR of the eleventh legislature (29 November 1988).

This same discourse would be possible from a Marxist perspective. That is, GMOs are not in themselves sinful (Christian perspective) nor do they constitute in themselves an affront for the working class (Marxist perspective). The same social and economic consequences (monopoly, dependence, unemployment, etc.) are denounced in the papal encyclical and, from a Marxist perspective, could be assumed as demands typical of socialism. But under no circumstances does this condemnation mean replacing a hierarchical model with human beings at the top with another in which the moral and ontological status of people, plants and animals is the same.

Lastly, a legal example of the model that we are examining (pre-eminence of the human being with non-predatory obligations with respect to all other living beings) is constituted, in Spain, by the reform in 2010 of the Criminal Code:[11]

> Anyone who by any means or procedure unjustifiably mistreats a domestic or tame animal, causing its death or injuries that seriously endanger its health, will be punished with three months to a year in jail and special disqualification of one to three years from the exercise of any profession, trade or business that is related to animals.

As can be seen, the crime consists in unjustifiably mistreating a domestic or tame animal, whereby it is inferred that it is possible to mistreat it justifiably (previously "cruelty" was necessary for it to be a crime). This article would make the exploitation of animals and even, indirectly, bullfighting non-punishable (it would have to be decided whether or not the fighting bull, a human creation through selection and crossbreeding, can be classed as a tame animal), since it could be argued that the justification (which does not mean that we agree) is economic, folkloric, etc.

This modification of the Criminal Code is in accordance with article 45 of the Spanish constitution, which obliges the public authorities to ensure the "rational use of all natural resources", an expression that perfectly reflects the paradigm that we have examined: the subordination of nature to human beings, but at the same time a tacit prohibition of its rapacious and predatory exploitation ("irrational use").

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[11] Sole article 99 of Organic Law 5/2010, of 22 June, RCL\2010\1658.

3.2. "Anthropocentrism (1)" – "biocentrism (1)"

The second model, while still valuing the moral and ontological status of human beings, attempts to elevate the position of all other living beings and of ecosystems, to the extent of proposing measures that would be to the detriment, not of human survival, but of their economic growth, which would also have repercussions for scientific and technological progress.

The narratives that we can place in this line, and the justifications and ultimate aims, are very different from one another, and we obviously lack the space here to examine them in sufficient detail. We shall make do with citing them briefly, showing to what extent they not only coincide but also differ from one another.

3.2.1. Ecoliberalism

Historical liberalism generally belongs to the previous paradigm, as we have said. But that has not prevented some thinkers in that liberal / enlightened / rational / scientific tradition from taking a step further in favour of the protection of the environment and of animals in particular.

This is the case of the philosopher Jesús Mosterín. Although he is an outstanding philosopher of science, we could place his political thinking in the liberal tradition (not neoliberal, far from it) to which very famous authors like Ortega y Gasset or Isaiah Berlin also belong. His thinking can be summarized in the following ideas:[12]

a) He considers environmentalism and vegetarianism to be moral options. In line with legal positivism (Kelsen) he rejects the existence of natural rights, hence he maintains that animals or the environment lack intrinsic para-Kantian value. He simply considers that the conservation of nature and the avoidance of animals' suffering would be a higher moral stage, specifically, an ethics of compassion, the continuer of enlightened rational tradition. For this reason, he views his criticisms of bullfighting not just from the perspective of the animals' suffering, but also from that of cultural backwardness, as yet another manifestation of the gratuitous barbarity and

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[12] The work of reference, in this case, is *El triunfo de la compasión. Nuestra relación con los otros animales*. Alianza Editorial, 2014.

ignorance bequeathed by King Ferdinand VII and continued by the majority of our contemporary leaders.

b) This rejection of the existence of natural rights (which he calls a myth, although a useful myth) is what leads him to maintain that there is nothing to stop animals being granted rights, although responsibilities should not be demanded of them. The responsibilities would be ours towards them. And this legal act is as possible and legitimate as any other that has taken place throughout history, without it being necessary to base it on metaphysical axioms: "There are no arguments to postulate moral respect for all humans (including babies and different kinds of disabled and sick people) that are not also applied to large groups of non-human animals."[13]

He does not idealize vegetarianism, however. Besides reflecting on the effects on health and not advocating its imposition ("In favour of vegetarianism it may be said that [practised with caution] it benefits health; that it makes better use of the Earth's resources,"[14] 2014: 62), he does not hesitate to call some vegan movements "fanatical". Moreover, he shows us that environmentalism and the animal rights movement can hold contradictory standpoints, for example, when it is necessary to eradicate a species that has invaded a habitat that is not its own and endangers the rest.

c) Jesús Mosterín is in favour of research with GMOs:

> The greatest enemy of biodiversity is agriculture. […] The more efficient agriculture is, the more food it will be able to produce per cultivated hectare and the greater amount of natural land it will be possible to conserve. As certain genetically modified crops increase agricultural yields, the better it will be for nature. The spread of these crops in the USA has coincided with a reduction of farmland and an increase in woodland. […] today's world offers us thousands of reasons for alarm, but genetically modified crops do not seem to be one of them.[15]

Environmentalism is often identified with the visceral rejection of GMOs, hence the opinions of Jesús Mosterín are so important. His combination of the thoroughness typical of scientists and common sense lead

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[13] He uses the expression *humanes*, instead of *humanos*, as an expression inclusive of women. In the singular it would be *humán*.

[14] Mosterín, *op. cit.*, p. 62.

[15] Mosterín, *op. cit.*, p. 237.

him to state that GMOs could contribute to the conservation of ecosystems if they are able to maximize production and reduce the amount of land under cultivation. He considers that biotechnology could be the way to cease using animals for consumption and to reduce the land given over to agriculture with the combined action of stem cells and GMOs: "On that day we could rewild much of the surface of the planet now occupied by crop fields."[16] This explains why, for example, he sees no moral obstacles in cloning a lost child if the parents pay for it themselves.

In his book he also comments on how the death of monarch butterflies was put down to GMOs, specifically to Bt-corn (genetically modified maize), an accusation that lacked the slightest scientific rigour and which forced the author of the publication to retract.

d) Experimentation with animals. Jesús Mosterín implicitly acknowledges that experiments with animals are still necessary for biomedicine, the reason why he talks of a "moral conflict" for which "no satisfactory solution has been reached (not even on a theoretical level)".[17] For this reason, he devotes many pages to advocating the replacement of animals, whenever possible, and reducing their suffering, with the European Union laws on experimentation with animals.

The complexity of moral dilemmas is clearly shown more than once by Mosterín:

> I would love it if there were there a general ethical theory that resolved all moral problems and dilemmas satisfactorily for us. But there isn't one, or, at least, I am not aware of it. [...] Although utilitarianism is the moral philosophy easiest to apply to our relationship with the other animals, it comes up against many other problems, beginning with its definition. [...] Nor is there a simple universal formula in ethics. If only there were such a magic spell, a sort of conceptual machine for justifying moral decisions. We would avoid so many dilemmas and headaches. I wish everything were easier, but it is not.[18]

In sum, using his own reasoning there are also contradictions: for example, GMOs are only safe, for both humans and ecosystems, if they are first tested on animals.

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[16] Mosterín, *op. cit.*, p. 166.

[17] Mosterín, *op. cit.*, p. 244.

[18] Mosterín, *op. cit.*, pp. 71-73.

3.2.2. Ecosocialism

Just as with liberalism, some socialist thinkers have reread Marxism from an environmentalist point of view and they have placed class struggle, the preservation of the environment and the protection of animals in the same bag.

This is the case of Jorge Riechmann, who, reusing a well-known phrase by Paul Valéry, "the age of the finite world has begun", analyses the human race's responsibility to future generations, non-human living beings and the biosphere as a whole. We could restructure his proposals in three ideas:

a) *An environmentalist rereading of Marx.* Riechmann begins by quoting Marx — "Even a whole society, a nation, even all simultaneously existing contemporary societies taken together are not the owners of the globe. They are only its possessors, its usufructuaries, and, like *boni patres familias* they must hand it down to succeeding generations in an improved condition" (Vol. 3 of *Capital*) — and the Marxist concept of social reproduction, to look in depth at the notion of sustainability:

> A socioeconomic order is ecologically sustainable when social reproduction can potentially be prolonged ad infinitum, because it does not endanger the ecological conditions and the environmental functions on which it is based.[19]

Given the Marxist nature of its formulation (our age would be that of "financialized fossilist patriarchal capitalism"),[20] sustainable development is impossible without modifying the economic and social structures of our societies.

b) *A duty to future generations.* Basing himself on Giuliano Pontara's principle of time irrelevance, Riechmann formulates the principle of diachronic egalitarianism towards future generations. It is basically the idea that our interests and preferences are not morally superior to those of future generations, so we must consider their interests (conserving the planet, basically) as if they were our own.

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[19] Riechmann, J. "Desarrollo sostenible: la lucha por la interpretación"; Riechmann, J. et al. (1995). *De la economía a la ecología.* Madrid: Trotta.

[20] Riechmann, J., Carpintero, O., Matarán, A. et al. (2014). *Los inciertos pasos desde aquí hasta allá: alternativas socioecológicas y transiciones poscapitalistas.* Granada: Editorial Universidad de Granada.

c) *Reinterpreting the principle of precaution through Jonas's principle of responsibility.* In his opinion, we have the moral duty to achieve sufficient predictive knowledge before continuing with large-scale scientific and technological progress. In fact, ignorance of the indirect or long-term consequences of our technological progress ought to lead us to postpone it or rule it out.

3.2.3. Peter Singer

The highly provocative ideas of Peter Singer are difficult to pigeonhole politically, and so, unlike what we have done with the two previous groups of theories, we shall refrain from categorizing them ideologically. We will briefly analyse his thinking in reference solely and exclusively to the issue of animals, summarizing his ideas in five points.

a) The expression "animal liberation" appeared for the first time in 1973, in a book review written precisely by Peter Singer.[21] He also used this expression as the title of a book published two years later. As he himself explains, until 1970 in the West only 94 studies had been published on this subject; in the following 20 years the number rose to 240 publications. It would now be impossible to count them.[22]

b) Based on a very well-known quote by the founder of utilitarianism, Jeremy Bentham — "The question is not, Can they reason? Nor, Can they talk? But, Can they suffer?" — Peter Singer reaches the conclusion that the moral equivalence between animals and ourselves is due to their ability to suffer and feel pain. The existence of a nervous system and the empirical verification of their behaviour ("shaking, facial contortions, moans, screams or other sounds, attempts to avoid the source of pain, the appearance of fear due to the prospect of its repetition, and so on, is present")[23] support his thesis.

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[21] Singer, P. (1973). *The New York Review of Books*, review of *Animals, Men and Morals*, by Godlovitch and John Harris.

[22] We will take his ideas from an article published in *The New York Review of Books* no. 8, of vol. 50, 15 May 2003, translated by Margarita Martínez, and from his book *Liberación animal. El clásico definitivo del movimiento animalista*. Madrid: Taurus, 2011.

[23] Singer, P. (2011). *Liberación animal. El clásico definitivo del movimiento animalista*. Madrid: Taurus, p. 27.

c) Richard D. Ryder was the first to use the neologism "speciesism", and it was subsequently reused by Singer. This term became so important that in 1989 it was included in *The Oxford English Dictionary*. Although the concept did not satisfy him all that much, with this expression he alludes to the "prejudice or partial attitude favourable to the interests of the members of our own species and against those of others". Thus, "In order not to be speciesists we must allow beings that are not similar in all relevant aspects to have a similar right to life, and the mere belonging to our biological species cannot be a relevant moral criterion for obtaining this right".[24]

"Speciesism" is comparable to racism or sexism. Singer reminds us that the famous book by Mary Wollstonecraft, *A Vindication of the Rights of Woman* (1792), was refuted by another one with a similar title, *A Vindication of the Rights of Brutes*, by Thomas Taylor, in which he asked if animals ought to have the right to vote as well.[25] From his perspective the justification for mistreating animals is comparable to the justifications that have been used historically for racism or the discrimination of women.

d) Equality between animals and humans. Singer argues that the acknowledgement of equality between human beings is not linked to effective equality in birth, talent, expectations, contexts, and so on. In fact, he considers it an achievement that these differences, inherent in our species, do not result in differences in treatment between human beings. To understand how he makes the jump to dialectical equivalence between animals and humans, we must read his thoughts on equality:

> The principle of the equality of human beings is not a description of supposed real equality between them: it is rule relative to how we should treat human beings. […] It is possible that one day all significant differences may be identified as environmental and not as genetic, and everyone opposed to racism and sexism will hope that it is so, as this would make the task of putting an end to discrimination much easier; but anyhow, it would be dangerous for the struggle against racism and sexism to be based on the belief that all important differences have an environmental origin. […] The right to equality does not depend on intelligence, moral capability, physical strength or similar factors. Equality is a moral idea, not the statement of a fact. […] The principle of the equality of human beings is not the description of a supposed real equality between them: it is a rule of behaviour.[26]

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[24] Ibid. p. 35.

[25] Ibid. p. 17.

[26] Ibid. p. 22.

From this perspective it is irrelevant that animals cannot be subjects, in liberal mythology, of a social contract, or that they cannot be the object of responsibilities, or that reciprocity cannot be demanded of them. Animal equality would simply be a moral ideal that mankind ought to achieve. He gives the example of Thomas Jefferson, who, although he “was incapable of freeing himself completely from his past as a slave owner”, advocated interracial equality in the belief that blacks were inferior to whites in intellectual capacities, a belief that did not hinder, from his perspective, the struggle for equal rights.[27]

e) Obscure areas in his thinking. The European Convention on Human Rights in Biomedicine and Biotechnology was not called, in his day, the European Convention on Bioethics, because this discipline was associated with utilitarian thinking, specifically, with Peter Singer.[28] To avoid a biased interpretation, the best thing is to let him speak:

> We thus conclude that rejecting speciesism does not imply that all lives have equal value. [...] It is not arbitrary to think that the life of a self-aware being, with the power of abstract thought, to project his future, complex acts of communication, and so on, is more valuable. [...] If we had to choose between saving the life of a normal human being or that of a mentally handicapped person, we would probably choose to save the normal one; [...] But if the dilemma consisted in just one of them avoiding pain [...] how we should act is not at all so clear. The same thing happens when we consider other species. [...] This would mean that if we had to decide between the life of a human being and that of another animal, we would choose to save the life of the human; but there may be special cases in which the opposite could be maintained, due to the fact that the human being in question did not enjoy the capacity of a normal one. [...] when we refer to the members of our species that lack the normal characteristics, we can no longer maintain

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[27] Ibid. p. 22.

[28] “Specifically to demonstrate the document’s legal, and not merely ethical, nature, the original title was changed, which included the term ‘bioethics’, and it was replaced by ‘biomedicine’. This change can also be explained due to an ideological reason: the word ‘bioethics’, which has been carefully omitted throughout the entire document, had caused serious resistance, in Germany especially, because it is usually identified with a utilitarian approach to bioethical dilemmas and in particular with the ideas of the controversial Australian philosopher Peter Singer. With the title eventually used it is clear that the Convention is ‘law’ in the strictest sense, and not purely ‘ethical’, even when there are huge points in common between both disciplines in this subject.” Andorno, R. (2001). “Hacia un derecho internacional de la bioética: el ejemplo de la Convención Europea de Derechos Humanos y Biomedicina”. *Revista Electrónica de Estudios Internacionales.*

> that their lives must necessarily be preferred to that of other animals. […] As long as we remember that we should give the same respect to the lives of animals as we give to the lives of those human beings at a similar mental level, we shall not go far wrong.[29]

I do not believe it is too mistaken to interpret that, according to his arguments, if there was nothing else for it but to carry out experiments in biomedicine (a life or death case, for example), we would have to prefer to do it with "not normal" humans, rather than with "normal" animals.[30] A similar idea has been put forward by the philosopher Ray Frey.[31]

One of the most surprising things about these movements of equating animals and humans is the ease with which some acknowledge the possibility of carrying out experiments with disabled human beings, as long as "normal" apes or pigs are protected. Surprise turns into dismay when we see that Singer, for example, comes from a family of Jews murdered in the Nazi extermination camps.[32]

3.2.4. Other forms of environmentalism

Ecofeminism, the members of Liberation Theology, peasant, pro-indigenous and anti-globalization movements, and so on, could, although for different reasons, be grouped together in this paradigm. For reasons of space, we are unable to look at their postulates in detail.[33]

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[29] Singer, *op. cit.*, 2011, pp. 37-38.

[30] The nuances are important: "This does not mean that in order to avoid speciesism we have to maintain that it is as reprehensible to kill a dog as it is to kill a human being *in full possession of their faculties*" (Singer, *op. cit.*, 2011, p. 35, our italics).

[31] "Some moral philosophers who have dealt with the subject, such as Ray Frey, accept a limited use of mentally subnormal humans and non-human animals as subjects for experimentation, acknowledging that there are no arguments for giving greater moral consideration to mentally subnormal humans than to other animals. Humans in full possession of their mental faculties, and chimpanzees and other superior animals, should be excluded from experimentation. Moreover, in certain experiments that are crucial for medical and pharmacological research, the best experimental animals (the best models of human reaction) are without doubt ourselves, humans, and then, the most sensitive animals and even chimpanzees, which actually exacerbates the moral dilemma posed." (Mosterín, *op. cit.*, 2014, p. 240). The quote by Mosterín is in the book by Ray Frey, *Interests and Rights: The Case Against Animals*. Oxford: Clarendon Press, 1980.

[32] He talks about his life history at the end of the book we have analysed.

[33] Their theses converge in the justification of the principle of food sovereignty. On this point, see López Baroni, M. J. (2011). "Los principios no originarios de la Bioética", *Revista Argumentos de Razón Técnica,* no. 13, pp. 113-149.

3.3. "Anthropocentrism (1)" – "biocentrism (1)"

The third model argues that the important thing is life on Earth, and that our species is a danger to it, hence we must reduce it to numbers compatible with the sustainability of the planet.

The most representative paradigm of this model is Norwegian philosopher Arne Naess's "Ecosophy T". The T symbolizes an isolated cabin in which he lived for much of his life.

The Norwegian upheld axioms based on an extreme egalitarianism of any form of life,[34] which would place human beings, with regard to ontological and moral status, on the same level as insects, for example. This way of equalizing nature ought to place his proposal in the previous model, as one of its variations; however, his discourse did not stop there, but he advocated reducing the human race to a number compatible with life on Earth, about 100 million.[35]

This form of intellectual pyromania is what causes us to place his discourse in this third model. Arne Naess did not take the trouble to explain how he intended to reduce the world's population, a detail apparently insignificant for his "deep" ecology. Therefore, some of his disciples tried to complete his proposal: causing famines in overpopulated areas to exterminate the surplus population.[36] These ideas were formulated shortly after the end of the Second World War, with the public by then fully aware of the Holocaust caused by the Nazis, something that was apparently no obstacle for Naess's neophytes.

Although the Norwegian expressly rejected this kind of idea,[37] his discourse undoubtedly lit the fuse. If human beings are placed on the same moral level as ants, there is nothing to stop it being taken a step further and humans being treated as ants.

The Earth would surely be better off without us, although life on the planet will more likely depend precisely on our technology in the long term. In any case, these debates can only be considered abstractly. The reality is that one thing is trying to reduce population growth by encouraging contraceptive practices, and another thing altogether is considering its forced reduction

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[34] Keller, D. R. (2008). *Encyclopedia of Environmental Ethics and Philosophy* – 2nd, pp. 206-210.

[35] Naess, A. (1973). "The Shallow and the Deep, Long-Range Ecology Movement. A Summary." *Inquiry*, vol. 16, no. 1, pp. 95-100; (1986). "The Deep Ecological Movement: Some Philosophical Aspects." *Philosophical Inquiry* 8, nos. 1-2.

[36] Augustin Berque, M. (1995). *De milieux en paysages*. Montpellier: Reclus, pp. 63ff, in Ballesteros, J. (1995). *Ecologismo personalista. Cuidar la naturaleza, cuidar al hombre*. Editorial Tecnos.

[37] Schwarz, W. (2009). *The Guardian*, 15 January 2009.

down to levels in line with the numbers proposed by someone who lived alone in a remote cabin in rich industrialized Norway, with its hospitals at the ready in case the pensive hermit should happen to fall in the snow.

3.4. "Anthropocentrism (0)" – "biocentrism (0)"

In this model we could classify the discourses that, under the guise of environmentalism, conceal another kind of programme that is not only damaging for all other living beings, but for the human race especially. Environmentalism would be a mask behind which to hide other types of objectives, like for example, racial supremacy.

Indeed, Luc Ferry recalled in a publication how in the 1930s the most advanced European animal protection legislation came from Nazism.[38] One of Hitler's aphorisms ("In the new Reich there should be no room for cruelty to animals") was the preamble for the Animal Protection Act, of 24 November 1933, the Hunting Law, limiting hunting, of 3 July 1934, and the Nature Conservation Act, of 1 July 1935.

It is essential to read some paragraphs of the Animal Protection Act, to get an idea of the dangerous mixture of ideas that lie behind an apparently environmentalist programme:

> The German people have always possessed a great love for animals and they have always been aware of the high ethical obligations that we have towards them. Even so, thanks only to the National Socialist Leadership, shared by very large circles, of an improvement of the legal provisions with respect to animal protection, the wish to enact a specific law that recognizes the right that animals possess as such to be protected by themselves (*um ihrer selbst Willem*) has been put into practice. […] Cruelty is no longer punished based on the idea that people's sensibility ought to be protected from the spectacle of cruelty against animals, men's interest is no longer in this case the background to the matter, but it is acknowledged that animals must be protected as such (*wegen seiner selbst*). […] from the point of view of criminal law, no distinction will be made between domestic animals and other kinds, nor between inferior and superior animals, nor between useful animals and those dangerous to man.[39]

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[38] Ferry, L. *El Nuevo orden ecológico. El árbol, el animal y el hombre* (translated by Thomas Kauf). Tusquets, 1st edition April 1994.

[39] Ibid. pp. 155 and 156.

Luc Ferry associates environmentalism with German Romanticism.[40] Regardless of the fact that there would be a lot to discuss about these issues, what we have read ought to serve to alert us to the risks of lowering the status of human beings, or elevating that of all other living beings (as Gustavo Bueno said ironically, the risk does not lie in equating the chimpanzee with the human being, but the other way round).

4. ASSESSMENT OF THE NARRATIVES

Environmentalism, our relationship with all other living beings and, in general, with the ecosystem, is part of the hard core of bioethics.

About the first model, "anthropocentrism (1)" – "biocentrism (0)", we could note on the plus side that it is the one that has made contemporary scientific and technological progress possible. Experimentation with animals is essential, these days, to be able to test new drugs or therapies before applying them to human beings. And the survival of our species has always depended on the consumption of animal protein, meat especially.

On the debit side, we must stress that it is the model that has led us to global warming and the objectification of all other living beings.

In the second model, "anthropocentrism (1)" – "biocentrism (1)", we could mention on the plus side that it is the one that has allowed us to become aware of the suffering caused to non-human living beings and the overexploitation of the planet. European legislation on experimenting with animals, without eliminating these experiments, is due in large measure to its denunciations.

On the debit side, we could demand of them a bit more coherence, for example, that they refuse any medical treatment that might have been tested first on animals.

About the third and fourth models we have nothing to say, as they speak for themselves. They remind us of the caution with which we must deal with these issues and labels.

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[40] "As the biologist Walter Schoenichen, one of the principal theoreticians of the protection of the environment, has insisted time and again, the laws of 1933-1935 constitute the culmination of the Romantic movement, 'the perfect illustration of the popular idea of Romanticism'." Ferry, Luc, ibid. pp. 148 and 149.

5. RECOMMENDED READING

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Bioethics is a field of knowledge that requires plural approaches and solid scientific foundations to analyse with sufficient rigour the ethical, legal and social consequences of biotechnology and biomedicine. For this reason, this Handbook of Secular Bioethics, the result of many years of teaching and research, is designed to provide the necessary information to those interested in the subject.

The ultimate aim is to provide arguments and proposals to encourage autonomy and responsibility, so that bioethical decisions enable the construction of a more transparent and democratic society. This perspective explains why the authors advocate the secular paradigm, based on the idea that the human rights acknowledged in international texts must form the universal minimum ethical threshold as a suitable legal and political model to ensure that these debates are productive and plural, and not merely based on beliefs, religious or of any other kind.

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