BIOETHICS:
A LOOK INTO
THE FUTURE

FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS
25TH ANNIVERSARY

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Barcelona, April 2023.

PROLOGUE

My father, Dr Víctor Grífols i Lucas, was a person who held very strong ethical principles both in his personal and professional life. He frequently stated that "it is possible to dream of a bright future if we continue to work while adhering to ethical standards. Nothing justifies a lack of ethics." It is these very principles that have been instilled throughout the Grifols organization, becoming part of its DNA.

Perhaps this is the reason why, 25 years ago, my brother Víctor Grífols Roura conceived the idea of establishing a foundation devoted to the study and promotion of bioethics. Given that we worked with plasma – a raw biological material – our work sat at the intersection of donors and patients. Embarking on such an initiative required the guidance of someone with a profound ethical perspective in this regard, and so he turned to Victòria Camps, then a professor of ethics at the UAB, to establish and lead the foundation, which would be named after our father as a tribute to his principles. When Camps was approached with the idea over lunch one day, she immediately accepted the appointment. After establishing a Board of Trustees to serve as the organization's governing body, the Victor Grifols i Lucas Foundation was born with the help of Rosa Avellà. From these humble beginnings, the Foundation has grown and evolved into what it is today.

For a number of years, this institution operated in a relatively unstructured manner, with the invaluable support of the Grifols company, which had always given it liberty to address pressing bioethical and socially significant issues independently. As its activities grew, it became necessary to expand its staff and appoint a director. Núria Terribas, a seasoned bioethicist with an extensive career in bioethics in Catalonia and passionate for the field, assumed this position. Thanks to her efforts, as well as the hard work of its team, the Víctor Grífols i Lucas Foundation has become a leading forum in bioethics.

Over its 25-year history, the Foundation has hosted numerous conferences, seminars, and debates, conducted numerous studies, and awarded and recognized many researchers and students with funding and awards. Until his passing in 2015, Dr Víctor Grífols i Lucas himself attended some of its events, and more recently, my brother Víctor has similarly lent his support to its activity. Both have witnessed with excitement how that initial idea has both become a reality and a powerful voice in the world of bioethics. Its Board of Trustees and jury members, who are appointed to select grant and award recipients, have played a crucial role in driving the Foundation's activities and promoting research in bioethics over the years. Thanks to their dedication and enthusiasm, they too have contributed to the positive image that this institution enjoys today.

We can proudly state that all of this effort has transformed the Foundation into a leading advocate in the field of bioethics, not only in Catalonia but across Spain and around the world. This commemorative book serves as proof of our success, featuring contributions written by key figures from our country and other parts of the world on vital issues that stimulate our thinking.

Congratulations and may it be for many more years!

Raimon Grifols Roura
Co-CEO of GRIFOLS

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CHRONOLOGY OF THE FOUNDATION

1998

Fundació Victor Grifols i Lucas officially founded on 23rd March 1998

First call for applications as part of its awards and grants programme on bioethics

The Foundation was presented to the public on 12th November 1998 in an event held at La Pedrera building in Barcelona

1999

First book published: *Libertad y Salud* (*Liberty and health*)

First collaboration with the Universidad Internacional Menéndez Pelayo

2000

First bioethics seminar with experts: *The Pharmaceutical industry and medical progress* and first bioethics journalism prize announced

2001

First debate on the ethics of scientific communication

2004

Introduction of new area of focus concerning the ethics of care with a seminar entitled *La gestió de les cures en infermeria* (*Care management in nursing*)

Launch of new era of focus on the ethics of cure

2006

Death of Josep Egozcue, vice president of the Foundation since its inception. To honour his memory, it launched an annual cycle of lectures in 2007. This event has since become one of the Foundation's most emblematic annual gatherings

2007

1st annual Josep Egozcue lecture with Daniel Callahan, director of the International Program of the Hastings Center in New York, who spoke on the individual good and common good in bioethics

2008

10th anniversary of the Foundation coinciding with the opening of the Grífols Museum

The *Interrogants Ètics* (*Ethical Questions*) initiative is launched, to foster debate on current ethical issues, the conclusions of which forming the basis for the subsequent collection of books

2009

Edition of the book ***Ethics in Nursing***

2010

Mark Siegler gives two lectures: ***The three ages of medicine*** and ***The doctor-patient relationship***

Discussion with experts on surrogate pregnacy.

2011

Death of Francesc Abel, patron of the Foundation and pioneer of bioethics in Catalonia on 31st December

First agreement signed with SESPAS to organize seminars on ethics and public health

2012

Lectures on ***Ethics and synthetic biology*** with Thomas Murray

The Foundation co-organizes European Forum for Good Clinical Practice (EFGCP) conference

2013

6th annual Josep Egozcue lecture series, with Carol Gilligan as speaker. The resulting lecture series book will be one of the Foundation's most read publications

The area of focus concerning education is started, with activities for the teaching community and the creation of the first prize for bioethics research work in secondary schools

2014

First annual *Ethics and Science* award announced

Peter Singer gives two lectures based on the topic of bioethics outside the clinical field

First edition of the Introduction to bioethics in Multidisciplinary Clinical Practice Course, conducted online

2015

Fundació Victor i Lucas and Universitat de Vic – Universitat Central de Catalunya create the Fundació Grifols Bioethics Chair

The Foundation partners with the Nuffield Council on Bioethics to conduct project on *Children and clinical research*

Death of Víctor Grífols i Lucas

2016

Collaboration with the CCCB in the +*Humans* exhibition

2017

Seminar on *Ethics and plasma donation*

First call for applications for the Foundation's Audiovisual Award

2018

20th anniversary of the Víctor Grífols i Lucas Foundation

Exhibition on the 50th anniversary of the Declaration of Human Rights

Launch of matinee film and debate series for secondary schools

2019

The Foundation organizes its first annual International Bioethics Congress

Start of collaboration with Amics de la Unesco Barcelona to organise cycles of conferences on bioethics

2020

More than 2,500 people participate in the webinars on COVID-19 organised by the Grífols Foundation Chair in Bioethics

2021

The Foundation receives the National Research Award for Scientific Patronage from the Government of Catalonia

2022

Organization of the second International Bioethics Congress

Tenth edition of the Introduction to Bioethics course organized with the Catalan Institute of Oncology

THE FOUNDATION IN FIGURES

\+
22,000

attendees to its events

€730,000

awarded in grants and prizes

110

research grants

2
international congresses

66
courses

60
seminars

51
lectures

64
publications

31
conferences

INTRODUCTION

On 23rd March 1998, the Victor Grífols i Lucas Foundation was officially established with the goal of promoting bioethics by encouraging dialogue between the sciences and humanities. Over the past twenty-five years, the Foundation has grown and expanded its activities, leaving a notable impact among professionals, scholars, and the wider public. Today, it is recognized as a prominent voice in the field of bioethics in Catalonia, promoting research, providing training and disseminating knowledge at different levels, including among younger generations who represent the future citizens of our society.

For its anniversary, it was the intention of the Victor Grífols i Lucas Foundation to publish a commemorative volume that diverged from the conventional corporate literature and historical texts often published on these occasions. Instead, the idea was to offer a book with content that would be of interest within the field of bioethics, which is the Foundation's *raison d'être*. This volume, therefore, offers a survey and analysis of selected bioethical issues and their future outlook. It is not meant to be an exhaustive review of the entire field, as the discipline is vast and constantly evolving with new questions and ethical issues arising from new knowledge and social changes. Instead, our goal was to offer a selection of the most relevant topics that we believe are representative of this discipline, not only viewed through a historical lens and but also one that is focused on the present and future. To achieve this goal, we called upon authors from different fields, including philosophers, researchers, scientists, and social experts, whose contributions represent some of the most pressing issues of our time. They offer a multidisciplinary perspective on different areas of interest for society-at-large, covering the bioethics of research, Alzheimer's disease, assisted reproduction, end-of-life decisions, genetic edition, and artificial intelligence, just to name a few. We have also taken care to respect the tenets of bioethics and the principles and values that sustain this discipline, in order to avoid the old adage "those who lose sight of their origins also lose their identity." The authors of the articles in this volume have collaborated with the Foundation throughout its trajectory, either continuously or occasionally, sharing their vision on bioethics and enriching discussions through lectures, courses, seminars, and publications.

This book also includes facts and figures related to the Foundation's work over its 25-year history, featuring a selection of our most significant milestones and a visual record of this time through photographs from our archives. The final section of the book pays tribute to the researchers who have received awards or research grants through our funding programme. We are proud to have contributed to their work, which has been essential to the development of bioethics in our country over the years.

Beyond being of interest to the reader, we hope that the book's contents will also serve as a testament to all the work completed so far, and that which still remains. The Foundation is committed to building a better society and providing a forum for ethical discussion that is crucial to decision-making at the micro-, meso-, and macro-levels, for all matters that affect our morally plural and culturally diverse society.

Victòria Camps Cervera
President

Núria Terribas Sala
Director

Bioethics: a look into the future

THE IMPORTANCE OF BIOETHICS

Victòria Camps

Twenty-five years ago, the then president of the Grifols company, Víctor Grífols i Roura, contacted me explaining his intention to create a foundation dedicated to ethics. The idea, already excellent in itself, was inspired by the deep-rooted conviction in the company that good practices are the best guarantee of a company's social and even economic success. I accepted enthusiastically the invitation to lead the creation of the new foundation, suggesting at the same time to limit its scope of work to the already many issues that were beginning to arise within bioethics, an emerging discipline whose purpose was the study of the moral dimension of life sciences with special concern for issues related to health.

The need to apply ethical knowledge to the problems of human life had arisen from the increasingly widespread confirmation of the existence of certain practices that would never be tolerated by anyone under the principle of human dignity. During the 1960s and 1970s, a series of declarations, namely, the Nuremberg Code, the Declaration of Helsinki and, especially, the Belmont Report, laid the groundwork for the ethical principles that would thereafter govern life sciences. Not only did these acknowledge the existence of actions that ignored the value of and respect due to human beings, but they also reflected on the need to address new issues arising with respect to assisted reproduction techniques and some timid proposals in favour of decriminalizing euthanasia. It marked the beginning of a movement that today brings ethics into all domains related to human and non-human life.

The development of bioethics has been very extensive, from both the theoretical and practical point of view and has been instrumental in the resolution of specific ethical problems. It has been deployed in academic institutions but also in committees created for resolution of ethical issues it is our duty to address at an individual, social and political level. The widespread existence and acceptance of hospital ethics committees is a notable example, these serving to designate, discuss and design proposals for protocols governing much of the activity of our health care system. The same is true for the committees established for reviewing clinical trial proposals whose express mission it is to ratify not only the scientific basis of this research but also its ethical soundness.

I will even venture to say that bioethics has deftly established itself as a model for the ethical principles guiding the development of professions in all of their variants. Although most professional activities, especially those having a direct impact on the lives of people, make attempts to introduce ethics into discussion on how their work is to be conducted, few have enjoyed the acceptance and development as that seen in bioethics. Logically those working in the fields of medicine and biomedical research are more aware of the risks that may arise in the absence of ethical controls, risks which arouse greater concern because they are more evident and verifiable. However, this should not serve as a justification for other professional domains to dispense with ethics as if it were something alien to their objectives and obligations.

There are three principles of bioethics according to the Belmont Report: beneficence, respect of persons autonomy, and justice. The innovation offered by this document is in the last two principles, hitherto ignored in medical and scientific practice. It is important to pay special attention to the principle of respect of persons, which until now has been the central issue in ethics. The obligation to inform the patient and request their

Victòria Camps was born in Barcelona in 1941, and holds the position of Emeritus Professor of Moral Philosophy at the Autonomous University of Barcelona.

Her professional career included a period as a member of the Audiovisual Council of Catalonia from 2002 to 2008, and she was chairperson of the Commission for Television Content from 1993 to 1996, a period during which she was an independent senator for the socialist party of Catalonia.

Victòria Camps has published numerous essays on ethics, political philosophy and bioethics. These include *Virtudes públicas* (Public virtues) (Espasa Prize for Non-fiction), *Una vida de calidad* (A quality life), *La voluntad de vivir* (The will to live) and *Creure en l'educació* (Believing in education). Her most recent books are: *El gobierno de las emociones* (Managing the emotions) (National Non-fiction Prize), *Breve historia de la ética* (A brief history of ethics), *Elogio de la duda* (In praise of doubt), *La fragilidad de una ética liberal* (The fragility of a liberal ethics) and *La búsqueda de la felicidad* (The search for happiness).

In 1999, she was awarded with the Josep M. Lladó Prize for freedom of expression and the Prize for Achievements in Education (Government of Andalucía); and in 2008 with the Menéndez Pelayo International Prize in 2008. She holds honorary doctorates from the universities of Huelva and Salamanca. In 2018 she was appointed Permanent Advisor to the Council of State.

consent for any invasive treatment or for inclusion in a clinical trial has been studied from all possible perspectives, to ensure it is implemented properly and preventing it from being reduced to a mere bureaucratic routine. The recognition of respect for a person's autonomy has proven essential in the liberation of assisted reproductive techniques as a way of respecting women's freedom to make decisions regarding maternity. Likewise, the debate on the decriminalization of euthanasia is based on the acceptance of the right to decide over one's life as one of the most basic expressions of individual freedom. The notion that patients are seen as free individuals who should be able to decide what is done with their body and life has led to the gradual but unceasing extinction of paternalistic care in medicine and related fields, in favour of more egalitarian carer-patient relationships based on mutual trust.

REALITIES BEYOND THEORY

None of these advances has come easily or without controversy. What is acceptable as stated in theory may work poorly in practice. For this reason, bioethics falls under the field of so-called applied ethics, based on the conviction that theorizing alone is useless if it is not contrasted with real situations that tend to arise in the margins of moral standards. To be able to practice bioethics properly, another basic element has been introduced: interdisciplinarity. Although the starting point is philosophical, since it is up to the philosophers to ensure conceptual rigour, tirelessly raising questions as needed, when ethics sets out to address real problems, it has no choice but to descend from its philosophical ivory tower and take note of what is said by professionals in other fields such as medicine, pharmacology, law, sociology, nursing, biology, or any other precise area of knowledge, in order to include aspects that are important to the problem at hand.

If the autonomy of the person has received all the attention from bioethics scholars, the same cannot be said of the principle of justice. Equal treatment in the protection of health and equal access to health systems, recognized in democratic states as a universal right, unsurprisingly leaves much to be desired. The expansion of neoliberalism since the 1980s interrupted the considerable advances made by European social democracies favouring the notion of a solid welfare state. Public health systems are still standing, but increasingly being stripped of resources, and efforts to ensure their sustainability have been insufficient. This became irrefutably clear during the pandemic. Today opinion increasingly tips towards the notion that the social problems derived from the major inequalities, the social determinants of health, poverty, migratory movements, and other aspects merit greater attention from bioethics. Furthermore, climate change and the ecological transition are also forcing a change in points of view that until very recently have failed to consider the plundering of nature as having a direct effect on human health, or on an ethical view of life in general.

A COLLECTIVE FRAMEWORK

In its twenty-five years of activity, the Víctor Grífols i Lucas Foundation has been a space for the discussion of issues that have arisen and developed within the aforementioned domains. It has tried to maintain the necessary interdisciplinarity to ensure a broad perspective in the handling of issues, largely achieved through the regular renewal of its board of trustees who members are appointed to ensure a plurality of viewpoints. Through seminars, conferences, lectures, research grants and awards, the foundation has attempted to foster a greater interest in bioethics among academic and educational institutions, health centres and society as a whole. Due to its special characteristics, the ethics of medicine and health in general is not alien to any human being. We all fall ill, get old, suffer in the face of poor health, be it our own or that of a loved one, reproduce and ultimately die; that is, the ethics of life directly affects key moments in the life of every single individual. Hence, what we decide to do in each case does not depend exclusively on personal and private decisions, but on a public deliberation fostered and encouraged by bioethics.

One of the pioneers in the development of bioethics in Catalonia and patron of the Foundation in its early years, Francesc Abel, placed special emphasis on defending the eminently secular nature of bioethics. It was not easy for him given his status as a Jesuit, yet he maintained this stance with particular tenacity and radicalism. Far from anecdotal, this perspective has a lot to do with the evolution of this special ethics of life. The issues are especially controversial if we consider that religious dogma has often ruled forcefully over the legitimacy of abortion, euthanasia, and even palliative care, all of which seek a more humane death. In today’s democracies, space should be given to discussion regarding important issues such as those involving the beginning or end of life which includes both religious and non-religious points of view. Although today there some disagreement still exists between religious and secular bioethics, it is the duty of those of us committed to spaces for thought such as that offered by the Grífols Foundation, to try to overcome this situation and promote discussion that is open to diverse ideologies.

Ethics comes into play when we encounter problems that go beyond the realm of scientific knowledge or expertise. These are questions that cannot be resolved through empirical or social sciences, such as law, politics, sociology, or anthropology. Instead, they are philosophical questions that require ethical consideration, particularly when they pertain to human behaviour and decision-making. The question, “What should I do?” takes on an ethical dimension when there is no clear answer provided by any science or discipline. In many cases, this question is not even raised because it pertains to issues outside the scientific knowledge. Addressing ethical questions requires a philosophical approach that takes into account the complexities of human behaviour and decision-making. However, while ethics is often viewed as a separate discipline from other fields of knowledge or sciences, this does not mean that ethical considerations should be overlooked. Ethical approaches are fundamental to our society, especially in relation to conflicts that affect people who aspire to behave as social beings. Additionally, many ethical issues are intertwined with scientific research and the development of new technologies. Thus, ethical considerations should be integrated into all aspects of society, including scientific research and technological advancements. The notion that empirical and social sciences are value-free has gained acceptance in recent centuries. However, it is a reductionist view to assume that objectivity and values are mutually exclusive. Indeed, the human perception of reality is always evaluative, and our conception of something as objective as disease and health is shaped not only by empirical data but also by individual and social evaluations.

THE QUESTION, "WHAT SHOULD I DO?" TAKES ON AN ETHICAL DIMENSION WHEN THERE IS NO CLEAR ANSWER PROVIDED BY ANY SCIENCE OR DISCIPLINE

This is because reality is a social construction, and the way we perceive and evaluate it depends on our individual and collective values. Thus, our understanding of health and disease is not solely based on objective data, but also on our subjective evaluations. While empirical data is essential for informing our understanding of health and disease, we must also recognize the role of values and ethics in shaping our perceptions and evaluations of these phenomena.

If this were not the case, how do we account for the WHO's definition of health as being "the state of complete physical, mental and social well-being"? When did this vision of health arise? What are the reasons behind this perspective?

THE ONGOING NEED FOR ETHICS

V.R. Potter, an oncologist, is credited with coining the term bioethics to describe a discipline that combines biological knowledge with moral values. Only from this perspective is it possible to seriously address the loss of our moral compass. This suggests that this crisis of values is not an exclusive or unusual phenomenon of our time. The evolution of ethical thought since antiquity shows us that the confusion between good and evil has always been present in our society, calling for a constant clarification of these notions and the building of a world where they could be plainly stated. That being said, the current crisis has some peculiar characteristics that require ethical discussion at many levels. Although we may share common moral values in theory and in the abstract, the priority we assign to them in practice often falls short. While many people may claim to positively value peace, equality, justice, respect towards others, and solidarity in theory, the reality in practice often falls short. This is due in part to what has been referred to as the *tyranny* of certain values, such as economics, which can overshadow other important values.

As a result, we may become overly focused on the cost or economic value of things, leading us to ignore or even have contempt for their inherent value.

In his book *Construyendo valores* (2013) Diego Gracia masterfully explains and offers a deep philosophical insight supporting the interconnection between facts, values and duties. Earlier on, it was shown that pure facts do not exist, and when they do, their importance is relatively minor. There is no argument as to what can be verified empirically. What is disputed is our appreciation of the facts, especially in relation to the way they should be assessed as this is where ethics come into play. It is at this point we begin to weigh the legitimacy of sacrificing one value for another in order to strike a balance between all values, since our conduct is guided by the duties arising from these considerations.

Accordingly, ethical thought or bioethics shows us that we cannot avoid certain issues that we feel are of no concern to us. Both individually and as a society, it is important to make the effort of making joint decisions in an effort to correct past and present mistakes. We must draw attention to any potential risks posed by scientific and technical change to ensure a better life for everyone, one that safeguards human dignity. In this era of unceasing technological change, one of our points of departure is the premise that not everything that is technologically possible is ethically acceptable. Quality of life is more important than a long life without prospects; that, at times, life may sometimes not be preferable to death. Thinking about all of this is very complex and inconvenient as it breaks with economic and cultural expectations whose underlying principles may on occasion be questionable; it is therefore essential that we look to all the different kinds of knowledge and perspectives, incorporating them into this dialogue. The very principles of bioethics reveal contradictions: beneficence and autonomy or autonomy and justice do not always combine harmoniously. Beyond specific solutions, it is more important to provide reasons supporting our decisions in order to introduce this kind of thinking into daily practice.

That this era is not conducive to contemplative thought or constructive discussion is quite evident to all of us. This difficulty can only be remedied by providing specific forums where such reflection and deliberation can take place. The domains of applied ethics have a function that is pedagogical, or educational. They instil a way of being in the world that runs counter to the fast pace and compulsive consumerism of today.

WORKING TOGETHER

The importance of bioethics ultimately lies in its educational or pedagogical role, and its purpose is to instil lifestyles that will help us work through our current crisis of values. This same ethical stance also emphasises the difficulty of reaching unanimous agreements on the meaning to be attributed to equity and the autonomy of the person, to name just two of the most important values of concern in bioethical debates. Determining the limits between one's values and those of another is no simple task and because there are no guarantees as to the consequences of our decisions, ethical reflection, in addition to being interdisciplinary, must also take place in a deliberative setting. We cannot make these decisions alone, as ethical issues arise insofar as we are social beings; they affect us all. Hence, committees, foundations and graduate programmes in bioethics represent ideal spaces for such thought, away from the hectic busyness of our modern world.

Although this thinking about our moral duty is no guarantee that such duties will be fulfilled and executed, it is a necessary condition for such outcomes. Aristotle warned us that teaching virtue is a practical task, not a theoretical one. Moral attitudes are consolidated through imitation and example (as do immoral attitudes). We learn how to be in the world through contact with others, adopting the customs of our surroundings, and imitating the individuals presented to us as models.

Thinking about bioethics is a collective and democratic task to be undertaken by society as a whole, not a handful of scholars or scientists. As our world sees greater improvements in science and technology, it is imperative that we rethink the meaning of life and death, of the contingencies accompanied by pain and suffering, or of the inequalities that debilitate millions of individuals living in inhumane situations. We must rethink how we age, how we treat the chronically ill or where to direct scientific research. Living well or with dignity is not an individual goal, but a collective one, for health is a primary good that must be distributed equitably. The right to live well must be ensured for everyone, and as long as this right is not truly universal, we must continue to question the morals behind our actions. ///

Bioethics: a look into the future

MEMORIES AND NOTES ON THE BEGINNINGS OF BIOETHICS IN CATALONIA

Marc Antoni Broggi

Catalonia has shown us the potential of bioethics, although in the past such work was difficult, and its visibility and influence were more limited than we would have liked. In this article, we will go through the founding of bioethics organizations, namely the Catalan Society of Bioethics, the Bioethics Committee of Catalonia, its Clinical Research Ethics Committees and Health Care Ethics Committees, and will enjoy a detailed survey of the establishment and development of bioethics in Catalonia.

On 26th and 27th April 1991, the symposium *La Bioética y sus comités* (*Bioethics and its committees*) was held in Barcelona, signalling the start of a new intellectual and moral movement in Catalonia. The symposium adopted the format of a similar event organized by the Council of Europe in December 1989 in Strasbourg through the CAHBI (Comité Consultatif Ad hoc de Bioéthique), which had brought together people who had hitherto known each other by name only, including Francesc Abel, Octavi Quintana, Diego Gracia, Josep Egozcue, Carlos Romeo Casabona, Javier Gafo, and Marcelo Palacios, some of whom in attendance at the Barcelona symposium held two years later.

When we proposed this event to the then Minister of Health of Catalonia (Xavier Trias), we had made sure to emphasise that all of this would cost little money, which, apart from the principle of the initiative and the promise of success, was perhaps the reason why he accepted. He believed in what we were saying, agreeing to sponsor the symposium under the auspices of the Health Ministry, and promising his participation in any work derived from its conclusions.

This symposium offered an introduction to bioethics presenting its basic tenets and examining the possible impact of its dissemination; our concerns were in line with the stance coming from the United States which defended bioethics and was critical of the *status quo*. We wanted to imagine initiatives that would develop the field, either as a discipline worth conveying to others, as a method to be applied in cases involving difficult clinical decisions, and to ensure safe research; but we were also keen to introduce a new culture that favoured more respectful and open-minded attitudes ("more humanized", we liked to say) among professionals and government. It also represented an opportunity to meet others in the field who felt the need to develop greater responsibility in this regard and who shared a desire to work with others in the analysis of such complex issues. Out of this event came the agreement to create multidisciplinary spaces for deliberation in the form of ethics committees. Emphasis was placed on adequate training to ensure a successful outcome. No one doubted that this new culture would ensure more effective and rewarding professional assistance and greater security for citizens. The feeling was that this new stage opened door to a new world.

FRANCESC ABEL, PIONEER

All of us know that before all of this, Francesc Abel was the true forerunner of bioethics. He worked alone in the field for many years, establishing the Borja Institute of Bioethics in 1976 —the first centre of its kind in Europe— with the support of the Society of Jesus and Hospitaller Order of St. John of God. He promoted the creation of an Ethics Committee at San Juan de Dios Hospital in Esplugues, published articles on bioethics in the journal *Labor Hospitalaria* and

Marc Antoni Broggi is a surgeon. Doctor of Medicine and Surgery, from 1991 to 2008 he was head of the General Surgery Service of the Germans Trias i Pujol University Hospital in Badalona. He is also a full member of the Royal Academy of Medicine of Catalonia. In the field of bioethics, he has served on the College of Physicians of Barcelona Ethics Committee and currently chairs the Bioethics Committee of Catalonia. Author of several articles, papers and conferences on bioethics, he has specialized in topics related to the doctor–patient relationship, clinical information, informed consent and advance directives.

put together a very comprehensive collection of bioethics-related texts at the Borja Institute in Sant Cugat (a place of pilgrimage and learning for many of us at one time or another). He also founded, along with four other European centres, the European Association of Centres of Medical Ethics (EACME).

It is also important to mention the previous existence of earlier circles interested in expanding upon the scientific-technical field to include concerns related to how patients cope with disease and how to better support them. An example of this was the GAPS Group, part of the first College of Physicians founded during Spain's transition to democracy. It is also worth noting the emergence of the first quality units in hospitals (by Rosa Suñol and Rosa Delgado) and the first Patient Service Department (under Virtudes Pacheco of the Sant Pau Hospital). Nor can we forget the pioneering and tireless work of Xavier Gómez-Batiste in the field of palliative care, who, under the auspices of the *Vida als anys* programme launched the Palliative Care Pilot Project in 1990, or the creation of the Right to Die with Dignity (DMD) association, founded in Catalonia by Salvador Pániker. All of these initiatives reflected a growing concern with how patient care was provided and interest in defending these values.

Furthermore, there were a number of isolated medical professionals who also shared this concern, namely, Jordi Gol, who singlehandedly garnered public interest in the topic when he insisted on being a doctor "of people and not only of diseases". This slogan became a veritable mission statement for many of us. We were a generation that hoped that the new universal health care programme we were a part of would be both more scientific and more humane. However, after years of work in the system we were perplexed to find that it often was more scientistic, rigid in its protocolized criteria and institutional routines, and that it sometimes was disrespectful and unkind. We witnessed a growing discontent among patients and their families (an attempt was made to call them clients), which we medical professionals perceived as ungratefulness.

The complaints were not due to the technical quality of physicians, which had improved dramatically with the introduction and widespread application of the MIR training system. Citizens were calling for a different kind of doctor-patient relationship, and confusion among medical professionals grew, along with the threat that it would drag us into a more irrational medical practice, one that would now need to be more defensive. While physicians may have known their patients personally in the old days, we weren't longing to return to that time. The traditional doctor-patient relationship was often paternalistic, distant, discriminatory, and lacking in medical controls. It was also marked by greater inequality and insisted on the patient's blind trust, which was sometimes mistaken for submission.

But more importantly, it became increasingly clear that the solution to these problems was not merely technical in nature; it required some knowledge of ethics, a field we were not familiar with. The professionalism that governed our work now compelled us to apply our critical eye to these concerns with the same intellectual and moral integrity we applied in the diagnosis of disease. Furthermore, bioethics gave us the rationality we were looking for. It helped us account for the changes around us and to accept some suitable solutions. To us, it therefore represented a scientific contribution to medicine because it improved our understanding of reality, and we enthusiastically adopted it with a transformative optimism that may now seem naive.

THE FIRST JOINT ROADMAP

And so it was: at the 1991 symposium, objectives were openly discussed and agreed by everyone, means were successfully defined, and a timeline was set. And suffice it to say, much of the programme was actually fulfilled. In three months, the Catalan Society of Bioethics (SCB) at the Academy of Medical Sciences (ACMCB in Spanish) was founded, a training course had begun at the Institute of Health Studies (IES) and an Advisory Committee on Bioethics of the Department of Health that would be the seed of the current Bioethics Committee of Catalonia (CBC) was created.

Francesc Abel was immediately nominated to be the first president of the new Society of the SCB. He declined this reasonable offer citing an argument that would have major repercussions for the future of bioethics in Catalonia, demonstrating both his broad vision and generosity. He argued that as a Jesuit priest, it would leave an undesirable mark on the Society, and it was important that its plurality be established at the outset, free from any ideological or religious ties. The members of the SCB management committee were: Francesc Abel, Màrius Morlans, Jordi Camí, Lidia Buisán and myself, with Francesc Vilardell as president, appointed to take advantage of the fact he was also president of the Council for International Organizations of Medical Sciences (CIOMS). The SCB wanted to support other organizations affiliated with the Academy in the discussion of bioethics as it pertained to their specific fields and

HAVING WORKED ALONE IN THIS FIELD FOR MANY YEARS, FRANCESC ABEL WAS THE TRUE FORERUNNER OF BIOETHICS, FINALLY FOUNDING THE BORJA INSTITUTE OF BIOETHICS IN 1976 to also be a meeting place for members and other interested parties. The society accordingly invited experts such as Diego Gracia, Adela Cortina, Carlos Romeo Casabona, Fernando García Alonso, James Drane, Victòria Camps, Javier Hernández, Moisés Broggi and Xavier Gómez-Batiste to enlighten us. In addition, it was determined that a single annual conference for all Ethics Committees would be held in different locations across Catalonia instead of a fixed headquarters, something which is still in practice.

Training was first provided in the form of a course organized and directed by the IES under the direction of Francesc Abel. It included an introduction to the foundations of Bioethical theory and practical training in the handling of clinical and research issues. But demand soon began to grow and a greater diversity of training courses were made available. The Borja Institute developed its own programmes, offering training courses for health professionals and more formal training later on, initially in collaboration with the Universitat Autònoma de Barcelona (UAB) and afterwards as part of Ramon Llull University (URL) under the direction of Nuria Terribas.

In 1994, Professor María Casado launched an official master's degree in Bioethics and Law at the University of Barcelona (UB), explicitly maintaining a secular perspective and creating the Bioethics and Law Observatory. She would later secure a UNESCO Chair and establish close ties with Latin America.

The UB's philosophy department also began offering a course on citizenship and human rights featuring a bioethics unit directed by Professor Margarita Boladeras. Xavier Clèries also taught an excellent course on communication with patients for medical professionals, to address a shortfall that eventually became latent: doctors that once hid bad news from the patient now had to share it with them –quite a difficult leap to make.

The creation of the Víctor Grífols i Lucas Foundation in 1998 broadened the range of available training courses, both academic and informational. Conferences, symposiums, courses, publications and applications for awards and grants followed one another with regularity, ensuring excellence in the most pressing topics. It has been an institutionthat has enriched the array of content and writing in the realm of bioethics over the last 25 years. Prime mover Victòria Camps still presides over the foundation today. It joined forces with the Vic University (UVic-UCC) under the direction of Núria Terribas, creating the Chair of Bioethics Fundació Grífols in 2015.[1]

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[1] The list, neither here nor in other areas, is not and cannot be complete. No exhaustive historiographical study is intended, but a simple remembrance of that time without consulting each of the references. Therefore, errors or absences are attributable only to lack of space and the unknowns of personal memory.

More courses popped up here and there, often with a patina that was overly formal and academic. Because they were expected to convey some knowledge, such courses offered an introduction to some principles and cited some of the field's most venerated texts, resulting in learning that was far removed from real life. In addition, they were often given with a marked ideological bias –from both sides of the moral spectrum. Early on, we recognized that clinicians who have an interest in bioethics require more than formal solutions. Instead, they need to be sensitized to the importance of respecting and understanding the needs, expectations, fears, questions, and rights of the people they treat.

As for the second objective of the 1991 symposium regarding the creation of committees, it was decided to separate Research Ethics Committees (REC) from Health Care Ethics Committees (HEC) to facilitate decision-making in the domain of health care.

BIOETHICS IN THE ADMINISTRATIVE ENVIRONMENT

Another key decision was the establishment of a Bioethics Committee within the Department of Health. The initial work of the original advisory committee began by establishing a series of useful instruments to help prevent fraud, leading to the creation of the REC Accreditation Order. Here, certain requirements were specified for an Ethics Committee to be recognized as such (to be plural and multidisciplinary) and to be able to validate, approve, and monitor research projects. An ethics committee was established in every centre that conducted research with a pharmacologist on staff. This was done to prevent unethical practices, but this work soon became routine and purely administrative in nature, ceasing to have the critical impulse that had previously characterized it. Issues in research gradually moved to other spheres of deliberation, such as the SCB and the Bioethics Committee of Catalonia (CBC).

Later, in 1993, the Committee recommended accreditation for the Health Care Ethics Committees (HEC). It was felt that this accreditation should not be imposed from the government, but the result of a need felt from below. While creating the new committees, it was important to strike a balance between offering support and preserving their independence as their success would depend largely on the acceptance of medical professionals in this regard. It was equally important for members of the committee to avoid adopting an attitude of assumed expertise or that of moral policing. Rather than making decisions for professionals, the committee should aim to foster dialogue and offer guidance.

I believe that all these goals were achieved. The first truly plural healt care ethics committee, that of Parc Taulí de Sabadell and led by Pablo Hernando, was a key example to follow. Then came the ethics committee of Vall d'Hebron Hospital, under the direction of Màrius Morlans. Both worked extensively on the creation of these new health care ethics committees. Although cases for discussion were infrequent, the HECs were highly valued by all those who worked with them, cultivating a culture of serious and responsible dialogue wherever they were established.

With the establishment of HECs and mRECs, the CBC was better equipped to address the needs of citizens in an open manner. They were able to respond to queries and provide guidance on a range of ethical issues through the publication of informative texts, making themselves known to the public. One such example was the awareness campaign on Informed Consent (IC), considered a practical expression of one of the basic and most important rights of the patient. A new symposium organized by the Department of Health on this topic held at the Germans Trias i Pujol Hospital, aroused much interest and boasted the invaluable presence of the pioneering bioethicist James Drane, from the PennWest Edinboro University. The conclusions resulting from this event led to the preparation of guidelines and conferences that were organized afterwards. It was emphasized that Informed Consent should be the result of a joint decision made verbally between doctor and patient. It should not be seen as a perfunctory formality imposed simply as legal protection for clinical or research actions.

The failure to achieve the latter objective was largely due to resistance towards the new culture of bioethics now familiar to all. Many professionals believed that the alternative to paternalism was simply a contract, which was a widespread and notable error. Contracts can help ensure high-quality, technically sound medical care in an emergency whilst ensuring the minimum level of respect and courtesy for patients. Unfortunately, professionalism is often associated with a colder view of the patient that focuses on their illness and not on them as a person (perhaps attributable in part to the use of computer screens). This inertia is a significant obstacle to change.

But the most corrosive instance of defensive medicine is that associated with the paradigmatic case of informed consent, this time one imposed by the government itself. A striking example of this was seen at a conference in Madrid organized by INSALUD under the direction of Javier Sánchez Caro. Here, the juridification of the written IC was clearly evident. And the subsequent changes applied to it only worsened the situation: with each new instruction, court sentence, and interpretation, the IC became increasingly burdensome, impeding its capacity for personalization, dashing the hopes of those of us in the field of bioethics who had hoped for a more patient-centred and flexible approach to informed consent. The resulting rigidity demonstrated medical professionals' utter mistrust of the initiative. Sadly, they applauded the IC as they felt that if they weren't able to act independently then it was preferable to be given exact instructions on how to proceed at all times and to be able to follow a set of standard procedures that saved time and reduced risk.

Despite issues such as these, this new bioethical culture has left its mark and considerable progress has been made in the last 20 years. Communication with patients and their loved ones has greatly improved and their decisions are now given the respect they deserve, indicating that this cultural shift is here to stay. Furthermore, this viewpoint rapidly spread and evolved among nursing staff. This has played a crucial role in enhancing the way system users, or patients, are treated.

THE LIVING WILL

The CBC has also made its contribution to the living will. It offered opportunities for open discussion about the topic, serving as a compass for existing and future situations, not only clinical practice, but also in other fields as well, such as its work with the Advisory Committee on Assisted Reproductive Technology. The CBC also played a crucial role in advocating for legislation on euthanasia. During the plenary session of the Parliament of Catalonia in February 1997, at the request of the DMD (Right to Die with Dignity), the CBC spoke to legislators, despite the fact that Catalonia had no competency in this area. This led to its advisory role in the implementation of a living will regulating end-of-life instructions –something that did fall under its jurisdiction. After hearing several testimonies, a report was prepared recommending the passing of a law to ensure proper implementation of the *Documento de Voluntades Anticipadas* (Advance Directives Document, or DVA in Spanish). The law would also permit the appointment of a patient representative. The draft law we proposed not only concerned the DVA, but also defined and included many scenarios in connection with patient autonomy, addressing a number of shortcomings of the General Health Act, in line with the Oviedo Convention (1997). Furthermore, our proposed draft law included various suggestions arising from the joint meeting on the regulation of medical records between the Spanish Ministry of Health and Consumer Affairs and the General Council of the Judiciary, in which we participated.

This pre-legislative initiative would serve as a basis for the structure and text of what would become Law 21/2000 passed in the Parliament of Catalonia on patient autonomy, representing a turning point in these matters both *de jure* and *de facto*. The unanimous approval of this legislation by all parliamentary groups in Catalonia underscores the vital role played by a robust culture of bioethics, which went way beyond the support of the committee. This law was replicated in other regions of the Spanish territory, leading to the enactment in 2002 of Spanish Law 41/2002 on patient autonomy, marking a major shift in the recognition of patients' rights.

During that time, bioethics was a novelty, with its own refreshing appeal. It helped medical professionals to overcome their biologistic short-sightedness, but also incited scholars of philosophy to leave their academic circles and head down to the public square to discuss real problems. And for legislators, bioethics encouraged them to recognize the dangers of excessive standardization.

The CBC continues to produce texts on bioethics to an exacting standard. It is proof positive that having a central forum that encompasses diverse perspectives is crucial to ensuring pluralistic dialogue. That's how it can safeguard citizens' rights without the ideological biases and political self-interest often seen in other more homogeneous forums. It holds credibility with society-at-large because it has managed to maintain the following basic characteristics: It is truly plural and not partisan; multidisciplinary whilst eschewing corporatism; independent from but respectful of government; its focus on values extends to domains other than the purely legal; it understands the complexity of issues and does not simplify them; and it never forgets its role as advisor. In 2005, it took an important step forward under the presidency of Victòria Camps, becoming directly dependent on the government of Catalonia, and not the Health department. For the past 30 years, it has maintained a stable and peaceful trajectory, despite partial members renewals, and has developed the ability to reach consensus through more than just negotiation.

I believe that Catalonia shall serve as an example of what is possible in bioethics, despite the difficulties and the reduced visibility and influence of certain initiatives. Unfortunately it is impossible to mention here all those who have disinterestedly and tirelessly played a part in the development of bioethics through their support of and participation in committee deliberations, analyses, and consultations at the CBC, as part of committees and HECs, as well as those who have participated in our seminars and courses. It is impossible to mention all of the names of all the people we met along the way. On the occasion of the 25th anniversary of the Víctor Grífols i Lucas Foundation, I would like to extend a collective thank you to everyone involved. It's fitting moment to remember them. ///

Bioethics: a look into the future

THE ETHICS OF CARE

Marian Barnes

The origins of the ethics of care in developmental psychology indicate that it is not a professional ethics. It does not offer a didactic basis for behavioural codes that must be followed by nurses, social workers or others in the caring professions. But it does offer a useful framework for reflective practice, has been applied to a wide range of human service practices and can enable creative dialogue between people with very different starting points to address the question of how we can live well in the world.

I was first invited in 2017 to contribute to a series of seminars in Barcelona organized by professionals who were working in the nursing college and sponsored by the Grifols Foundation. These professionals have formed themselves into the Minerva Collective with an aim of promoting the ethics of care within the health system. Their commitment is to deepening our understanding of care as both an ethical principle and a practice. Care is fundamental to nursing practice and it is a concept with which those working in this area are familiar. My background is rather different. I am a sociologist and have worked throughout my career in the applied social sciences. My work has had a particular focus on the lives of people as they grow older, people living with disability or mental health problems, on unpaid family carers, and on the policies and practices of welfare states in these areas. Within this field I have had a particular interest in collective action which has enabled people to give voice to their own experiences and to impact on public and social policies through involvement in research, co-production and participative governance. In this context justice has been a significant rallying call, but care has had a rather more ambivalent presence.

I came to work on feminist care ethics comparatively late in my career. I encountered it almost by accident when I saw a book called *Citizenship and the Ethics of Care: Feminist Considerations of Justice, Morality and Politics*,[1] by Selma Sevenhuijsen. The impact of this work was transformative for me. It enabled me to make sense of what had troubled me in campaigns that sought *rights not care* and which, in some cases, created divisions between those claiming identities as *carers*, and disabled people who rejected care as oppressive. As well as impacting work that I have undertaken subsequently, it has enabled me to reflect on earlier research, to better understand why care has been experienced and viewed as problematic, and offer deeper insight into the relational dynamics of issues I had been researching. This included issues often considered by reference to care, such as relationships between adult children and their elderly parents, but also political issues such as deliberation between disabled citizens and service providers that were not typically included within the context of care. Most recently I have co-authored a book on *Researching with Care*[2] with my colleague Dr Tula Brannelly that offers reflections on research as a caring practice.

Here I outline what I understand by the ethics of care and suggest why it is a necessary part of thinking not only about health care practices, but

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[1] Sevenhuijsen, S. (1998). *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics*. Routledge.

[2] Brannelly, T., & Barnes, M. (2022). *Researching with Care: Applying Feminist Care Ethics to Research Practice* (First). Policy Press.

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about broader policy and political thinking and action.

CLAP FOR CAREGIVERS

One early consequence of the COVID-19 pandemic was an increased visibility for care. This included, in the UK, a weekly clap for carers ritual when many people came out of their houses to join together to value the important work being done by, primarily but not exclusively, health professionals in this moment of extreme need. The profile of care workers was raised and the importance of *voluntary care* within communities recognized and celebrated. Some argued that this would be an enduring, positive consequence of the pandemic. Others of us were not so sure and, speaking from the UK, there is no obvious lasting impact in terms of recognition and valuing of care workers or of care itself in policies or reward systems. Care has retreated to its marginal position where those in power find it easy to ignore the necessity of care to us all. This marginality is evident in the way in which care ethics was originally formulated as a distinct ethical position by psychologist Carol Gilligan.

Gilligan's research was prompted by her wish to listen to the way in which children and young people sought to make sense both of their own moral dilemmas, and how they thought about moral choices in general. In particular, she wanted to include girls and young women in her research, because dominant theories of human development at the time she started work were based on research carried out exclusively with boys. Gilligan later described herself as someone who listens. As she listened she heard internal voices to which young women in particular had struggled to give expression, and that they had learned to suppress. She heard different ways of talking about moral decision making and it was this that gave the title to her ground-breaking book: *In a Different Voice*.[3] The different voices that Gilligan heard led her to distinguish an ethic of justice: the capacity to apply abstract moral principles to different circumstances in order to decide *right* or *good* actions which had been seen to indicate mature, adult development, and an ethic of care. The key principles of justice ethics she named as rights and rules, whilst the key principles of care ethics are relationships and responsibilities. The voice in which an ethic of care ethic is articulated is one in which the motivation behind deciding the right or best course of action is to sustain positive relationships. This involves attentiveness to the particularity of the situation and highlights a willingness to take responsibility for others and for relational wellbeing.

Gilligan's work has had a profound impact well beyond her original discipline of developmental psychology. The distinction and relationship between care and justice is one that

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[3] Gilligan, C. (2016b). *In a Different Voice: Psychological Theory and Women's Development*. Harvard University Press.

moral and political philosophers have debated extensively. For those of us researching and working in fields of human services and public policy, the basis of care ethics within a relational ontology has generated important insights for applied work. If the fundamental characteristic of humanity is interdependence rather than independence, then a concept of social justice based in individual autonomy is flawed, and practices based in individualism ignore what matters the most to people in terms of relational wellbeing. To move towards justice both policy and practice needs to be centred on relationality. Thus, in the context of the carer/disabled people example cited above, rather than focussing on the rights of carers or/versus the rights of disabled people, we should think about the relational impacts of disability and the way in which such relationships are constructed and conducted within broader social relations of power and inequality.

The origins of care ethics in developmental psychology indicate that it is not a professional ethics. It does not offer a didactic basis for behavioural codes that must be followed by nurses, social workers or others in the caring professions. But it does offer a useful framework for reflective practice and has been applied to a wide range of human service practices, as well as professional practice beyond the human services: to architecture for example. It is not a form of virtue ethics because its focus is on the relationship between workers and service users and the networks in which they are involved, rather than on the characteristics and qualities of the individual worker. So what is the ethics of care?

CARE AND ETHICS

My response to this lies in my introduction to this article. As a social scientist working across different fields of human service, sociology and social policy, care ethics has enabled me to develop deeper understanding of what matters to people and why as they respond to illness, disability, and ageing. It has offered me and others an analytical framework to critique policies and practices in terms of their capacity to deliver wellbeing and social justice. It has been a guide in the development of my practice as a researcher who cares about both the issues and the people I research. And as a woman growing older with friends and family members experiencing poor heath and in need of careful help from others, it has helped

PRACTICES BASED
IN INDIVIDUALISM
IGNORE WHAT
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TO PEOPLE
IN TERMS
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WELLBEING

me reflect on personal needs for care. For others care ethics has offered a transformative way of understanding our response to dying and to those who have died, and it has encouraged reflection on our responsibilities towards future generations. Others have used this approach to address the experiences of migrants and refugees; others to consider how the design of our physical environment might enable care, whilst others have extended care thinking into our relationships with other than human life, with soil and the way we treat the planet on which we live. Care ethics has multiple applications and can enable creative dialogue between people with very different starting points to address the question of how we can live well in the world.

The definition of caring that underpins much work on care ethics was offered many years ago by Berenice Fisher and Joan Tronto:

> *“On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web”.*[4]

In this definition, care is designated as purposeful – it is necessary to our capacity to live well in the world. Because humans are relational beings who are dependent on others for their survival, growth and nurture, this interdependence should be the starting point for any system capable of enabling wellbeing and social justice. There are times in people’s lives when dependencies are particularly evident and vulnerabilities expose the inadequacy of concepts of individual autonomy. We all needed care when we were babies; illness or disability present particular care needs and as we grow older many of us can expect to need some degree of personal care. But to disregard our continuing need for care marks what Tronto has called the ‘privileged irresponsibility’ of the powerful for whom the everyday care of others becomes invisible. We need both to care for ourselves and to recognize the care we receive from others.

The definition identifies interdependence beyond the human. It is increasingly evident that care for other animals, for soil, plants and landscapes is necessary for human survival and in their own right. We know that those least responsible for climate change are the ones suffering the worst impacts: environmental justice and social justice are connected and call for a caring response. The scope of care ethics is an expansive one; its usefulness draws from its applicability in diverse contexts.

I suggested elsewhere that we need to understand care as a way of

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[4] Tronto, J. (1993b). *Moral Boundaries: A Political Argument for an Ethic of Care*. Routledge.

conceptualizing personal, and social relations, as a set of moral principles, and as a characteristic of diverse practices. Tronto's articulation of the phases of care is another way of thinking about this. Both emphasize that care is much more than an individual virtue or compassionate response.

THE PHASES OF CARE

Tronto elaborated five phases of care, each associated with a related principle. Care starts with caring about – being attentive to others and noticing the need for care. Accepting responsibility and acting to meet the identified need is necessary if this awareness is to become taking care of (which can include designing and establishing services), and then enabling caring for – the hands-on work of care giving which is more typically the focus for analysis of care. For such actions to embody care they need to be undertaken competently. Care is not complete unless it is received: it is a relationship not a product to be delivered. So we also need to include care receiving – the responsiveness of the person being cared for. How care receivers respond to the actions of care givers feeds back to the attentiveness necessary for care to start and develop. And caring with – caring with others, including recipients, builds solidarity, a confidence that care is available when needed and a shared experience of the process of care.

This analytical framework can enable a guide to and a reflective analysis of the practice of care in different contexts, whether that be nursing, social work, child care, residential care or even probation practice. It encourages recognition of the networks involved in caring practices. If caring relationships are conceived only as the one-to-one interactions between care giver and care receiver then it is likely that the needs of care giver for care will go unrecognized, and the contributions of significant others will not be acknowledged. The "life sustaining web" that Fisher and Tronto name is not a metaphor but an existential necessity. As well as interrogating policies, a care ethics perspective has been used to analyse the organizations from within which workers seek to care. The inclusion of competence as an ethical principle cannot only be addressed to individual workers, but should be applied to the context within which they are asked to do their job. This framework can be used to look at interactions involving family members, friends and others in unpaid caring roles because it does not presuppose any particular task or skills. The competences necessary to enable good care are likely to be distributed amongst different people. Experience of introducing this framework to both health and social care workers and to old people involved in researching wellbeing in old age has demonstrated an immediate recognition of its value in both unpacking the different stages of care, and the significance of these in terms of the ethical principles involved. All reflect the relational ontology underpinning care ethics, and the contextual nature of caring practice.

FOCUS ON CARE

The ethics of care offers a distinct way of thinking about health care as one amongst many contexts for care:

- It helps us to think about the subjects of care. Care includes care of self and of known and unknown others. Those who are unknown may be distant geographically or generationally. Those involved in caring relationships include people paid to care and those for whom care is part of a close personal relationship. Care givers also need to receive care – both in their own right and to enable them to care. Caring relationships often involve more than two people: how caring networks operate impacts the way care is received and experienced. A failure to care for care givers (both paid and unpaid) undermines good care and represent a moral failure. Care receivers can also be care givers. The subjects of care include non-human animals, natural environments and material things.

- Care is political and both the nature and content of policy making impacts the capacity to develop caring relationships. A care ethics perspective can be used to interrogate policies to assess the place of care in comparison with other values. Policy analysis from an ethic of care enables not only critique, but renewal: what would policy based in caring principles look like? We can apply a similar approach to research intended to improve health and experiences of service use.

- The ethics of care thus offers a perspective that links the personal and often intimate practices of care to the organizational and political context within which social relations develop. It provides a language which helps us talk about the often invisible work of care and enables a critical and transformative analysis of policies and practices impacting experiences of justice/injustice. ///

Bioethics: a look into the future

ETHICS
AND SOCIAL SERVICES

Begoña Román

Social factors account for 80% of what determines our health, meaning that it is influenced by more than just medical concerns. However, despite the importance of these social aspects in the clinical sphere and in bioethics, they will always be overshadowed by the primacy of the physiological and the individual when it comes to health care. Although Engel called for a biopsychosocial model in the late 1970s and proponents of person-centred care sought the implementation of a more comprehensive approach to such care, it is still not clear what the term social actually means. Social services were created to address the social needs of individuals, and these needs tend to arise during times of significant vulnerability.

Around the same time that Engel called for the three-dimensional biopyschosocial model, the Belmont Report was being written (in response to the unscrupulous Tuskegee Study which experimented on vulnerable subjects), social service professionals believed that these rights should be universal, and not mere gestures of perceptible charity or well-meaning compassion. In this sense, the Spanish law on the Promotion of Personal Autonomy and Care for people with Dependency (2006) arose in response to the public administration's duty to ensure such care and promote autonomy for all affected citizens as a universal right, and not only for those groups traditionally considered vulnerable. This helped to destigmatize the perception of social services as being only for the poor.

Public services such as health care, social services and education, for example, arise out of a notion of justice, solidarity and interdependence in an effort to fight against the arbitrariness of biological and social conditions we have not chosen. Thinking about social services requires thinking about our societies, their institutions, laws, and supports, which are based precisely on the fact that no one is sufficient on their own. An individual is still a social institution unto themselves, their development as a person depends on the society that sustains them.

Overcoming that vision of social services as belonging to the poor, envisioning them as a universal right and therefore, as a matter of justice has proven to be quite a challenge. However, recent economic crises have entailed a return to paternalistic, handout-centred policies and social services for marginal groups.

This article is divided into two parts. The first part addresses the social aspects which should be given more weight in bioethics, a field that seeks greater integration in such concerns. The second part will outline the future challenges in making this possible. For this we need institutions that are fair, an objective that is impossible without the proper social diagnoses.

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In the same way that we observe the primacy of physiological materialism in health care (where sadness is reduced to a biochemical imbalance in the case of mental health, for example) we have also witnessed insufficient attention given to the individual's economic and social context, or limited it to their family relationships at best, leading to biases in the care given to them.

We believe that wealth often precludes the need for social intervention. This is seen in gender-based violence or in pathological intra-family relationships which are automatically attributed to economically vulnerable families more than among the affluent. Yet all of these individuals deserve to be protected from this structural violence.

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Individualism and physiocentrism are the ones that command attention. In so doing, only helping people on a case-by-case, dose by dose basis, the chances of improving everyone's health are reduced. It is not at all a matter of going to the extreme of totalitarianism and the sociologization of illness, but to emphasize instead the complexity of the multidisciplinary approach and how this perspective will allow for more chances of success and results in people's well-being. Community health and public health are attentive to these domains and the social ties they generate. Yet the pandemic showed how under-resourced and undervalued they actually were.

SYSTEMIC PASSIVITY

Our health care systems cannot continue to be blind to the human condition, which is interdependent on the functional social network that sustains it. With an aim to move beyond paternalism, bioethics fostered a greater respect for the autonomy of people. Immediately it was determined that this autonomy should be relational, that is, in keeping with the quality of the individual's relationships and other social aspects. This is especially relevant in social services for two reasons: Firstly, because for people whose spheres of recognition failed to provide them with basic moral resources in relation to social situations (such as self-confidence, self-respect or self-esteem), there is a tendency to develop adaptive preferences such as resignation and an uncritical acceptance of their circumstances. This owing to a feeling that they are undeserving, that they are not entitled to any rights, or that the systemic violence they are subject to cannot be changed. Second, when this occurs, we label the decisions they make, the ones that are expected of them, as being autonomous. As a result, they are not empowered. Instead, they are turned into obedient subjects who follow the guidelines of social service professionals, who at least are there for them, to guide them.

Beyond bioethics at the clinical level, social bioethics addresses this structural violence from multiple origins, in keeping with an ethic of care, serving as a complement to the more abstract ethics of justice for all in generic terms, each having identical rights and citizen's charter, along with one for individuals subject to unique circumstances and idiosyncrasies. The work of social services involves the development of capabilities and ties in the midst of chaos caused by the problems affecting individuals or communities. These problems may range from the fear of being evicted to the loss of employment due to long COVID-19 which has taken over life as we know it. Some sense of calm returns if the vital basics are guaranteed, when they know that they won't be left without a roof over their heads and will receive the care and support they need in the event of dependency. Yet once calm is restored, it is essential that we pay attention to the other two elements mentioned above, namely, their capabilities and social ties.

If their social ties are eroded due to stigmatization, marginalization or simply because they destabilize and generate dependency, they become pathological and the individual will not be able to build a good life for themselves that is appropriate or autonomous, one which can be enhanced by good health or hindered by illness. It is difficult to achieve a level of social cohesion necessary for this personal objective.

Social service interventions are also aimed at creating capabilities. This term refers to what people are capable of being and doing. And what you are comes from social sources. Healthy personal development depends on a person's spheres of recognition, namely their family, city and friends. Beyond seeing people in terms of what they are not capable of or what they cannot do, we should see their potential, what their life projects are. To create capabilities, willpower is not enough. We need to adopt a vision that considers what the person can do, without putting a spoke in the wheel, enabling them to develop their life projects. Hope occupies a fundamental place in this regard, and it shouldn't be the responsibility of the individual, but also that of society, allowing people to carve out and imagine futures, pulling them out of poverty or fate.

In short, expanding this perspective and the bioethical mindset requires reconsidering at least two of the classic bioethical principles as formulated by Beauchamp and Childress. On the one hand, the principle of autonomy should be more relational and social. On the other hand, the principle of justice should not only be addressed at the micro level and that of individual autonomy, such as the distribution of resources in the community, but also in terms of the type of public policies generated in the country. It refers, beyond the fight against poverty and for social rights, to the fair distribution of benefits and burdens, recognition, and social cohesion. Let us consider, for example, how COVID-19 mortality varied depending on the ideological basis of public policies followed, that is, the extent to which they espoused neo-liberalist ideals or not.

II

This section will explore some of the challenges that the ethics of social services will face in the future.

First, they include different forms of social vulnerability, such as immigration, population ageing, changing family structures and (digitally-mediated) social relations. Apart from the deficiencies in access to basic material goods and their negative effect on equal opportunities, we also face the risk of progressive *ghettoization*, a phenomenon often experienced involuntarily by some and not others. Thus, recreational centres are opened for children and youth whose parents cannot pay for extracurricular or other leisure activities and therefore these spaces are only used by the socially vulnerable.

Work at the community level, applied across domains, has been largely forgotten. We deal with individual cases of families or some groups, but little attention is paid to the dynamics operating in the neighbourhood. The institutions that ensure social cohesion are mainly schools, but may also be health centres, especially primacy care facilities. Loneliness and sadness among the elderly and/or dependent people could be improved by community and participatory actions, but these lack the appeal of the more spectacular, sporadic and anecdotal spring festivals or multicultural fairs.

In social services, local government is closest to the community and therefore the most suitable for identifying the needs of the population. It is essential not to excessively ideologize. This is a matter of rights, not the preferences of the current councillor or the eagerness of some teams to innovate, thinking that what worked in another neighbourhood will work for them. Consequently, depoliticizing social services by separating rights issues from policy preferences is another challenge.

THE CHALLENGE IS TO DEPOLITICIZE SOCIAL SERVICES BY SEPARATING RIGHTS ISSUES FROM POLICY PREFERENCES

Our increasingly digitized lives have brought about new types of social relationships and interactions with professionals. The ability to provide support and guidance without being physically present, as well as the option of instant access to professionals through rapid communication channels has opened up a range of opportunities for treatment, collaboration, observation, and even supervision. These developments challenge us to consider the nature of the ties that will be established and the degree of trust that can be developed when we are not physically present to offer support. Deciding when to be physically present and when to provide remote support requires ethical reflection.

SOLIDARITY ACROSS DISCIPLINES

Creating a more effective and less emotional form of solidarity and fraternity is a significant challenge that requires agents to collaborate across different sectors such as health, education, social rights, and others in a multidisciplinary fashion. Integrated social services and health care agencies are expected to contribute to this effort but are greatly hindered by the dispersion and diversity of the agents involved including various levels of government as well as not-for-profit and private entities and organizations. Moreover, we still lack shared social service records despite the advancements made to date.

The professionals who have been most successful in integrating social services and health care are those who care for people with functional diversity or mental health issues, precisely because they saw similar challenges faced by palliative care professionals vis-à-vis their medical counterparts: that a lot could still be done even when, medically speaking, treatment options were exhausted. Psychologists and psychiatrists have also realized that, in addition to diagnoses, treatments, and psychotherapy, it is essential for people to have a good quality of life in their daily activities. Professionals who support people with chronic and complex illnesses have also understood the importance of sharing care, rather than compartmentalizing it. They pay attention to the social dynamics generated by these illnesses, because life is what is happening every day, and cannot be lived temporarily, waiting for something to happen.

Indeed, one of the most distinctive features of the social dimension is the vast and diverse array of agents involved in social intervention, often in partnership with various public administrations. However, the proliferation of NGOs, foundations, and other associations, each dedicated to their own cause but whose converging aims serve to improve the day-to-day lives of people, can lead to arbitrary and uneven distribution of resources across regions. To obtain public subsidies, these organizations often find themselves in competition with each other, giving rise to a strange contest to see who can address vulnerability most cheaply. Nor is the promotion of cooperatives always the best solution, as this approach may stem from a profit-generating and investing motive, rather than a genuine desire to serve the public. While there is nothing inherently wrong with pursuing profits, that there is money to be made and a desire to do so in the care of the vulnerable should give us pause for thought.

Likewise, we must acknowledge the inherent challenges faced by professionals working in fields related to social services, such as social education, social work, and social psychology. These are relatively new professions dedicated to action and activism, which leave little time for reflection, writing, evaluation, and experience-based learning. To maintain the prestige of these professions, it is crucial for professionals to cultivate a spirit of self-criticism. One of the challenges is to train professionals in two key areas. Firstly, training in ethics is required in order to assume the complex double agency that their work demands. Secondly, they need training not only in ethics and deliberative capacity, but also in multidisciplinary and inter-institutional collaboration. Generally speaking, training courses tend to be too intradisciplinary and work with other disciplines comes too late, when jargon takes over and the effort and time to understand one another hinders efficiency. Given that social service professionals work in diverse settings (schools, associations, government services, etc.), but always in collaboration with other professionals, it is important that this collaboration begins during their studies. The implication being that such interdisciplinarity should be applied within the universities themselves as well as in curricular and extracurricular practices.

Ethics in social services research presents a significant challenge. This was already observed at the time of the Belmont Report, which called for further development of its guidelines on research in human and social sciences. However, there is limited awareness in social services regarding the requirement for a Research Ethics Committee. Even when such committees exist, they may not have any ties to a university environment (not uncommon in social services), which means that there is no committee that can validate such research.

Yet all of this fails to consider the challenges that are specific to the human and social sciences, which are not based on objective empirical evidence like the natural sciences or biomedicine. For instance, how do we create effective capacities and establish meaningful connections between housing-first policies and socio-educational commitments for homeless individuals? How do we evaluate the effectiveness of such initiatives? When dealing with individuals and their unique circumstances, objectivity is not always possible, and subjective evaluation is necessary. However, subjectivity should not imply arbitrariness. Here, we are referring to the difference between understanding (describing the effective causes) and comprehending (discerning the reasons and purposes). Scientific and clinical evidence is clearer, as are its successes. Evidence and successful outcomes in social services are influenced by a range of biographical dynamics without denying the fact that they may also be measured through other potential indicators whose determination may entail certain ethical challenges. Addressing individual cases in their unique contexts requires a nuanced approach, and homogenization is not always the best option, which adds another layer of complexity to social intervention and the evaluation of its impacts.

Health care ethics committees, which have been quite beneficial to the field of bioethics, can also be configured in relation to social services through the designation of spaces dedicated to ethical reflection, but they require spaces and time for this purpose, things they often lack. For this reason, we must also discuss their economic infrastructure, which is also a decisive factor in social services. As the pandemic has shown, care cannot always be provided in contexts of cost reduction and high staff turnover. The elderly, for example, who place a high value on the comfort of their day-to-day activities and routines find it difficult to adjust to changes. When their caregivers are subject to high turnover rates, their stability is affected and so are the bonds they establish with them. This also affects the capacities that they may still preserve but which new carers must discover. Sometimes, when we rush to complete our tasks, we may unintentionally impede the person we are caring for. For instance, we may hurry to dress them, not realizing that they are capable of doing it themselves, albeit at a slower pace. By taking the time to understand the person's capabilities and allowing them to participate in their own care, we can avoid inadvertently disabling them and promote their independence.

The pandemic highlighted how important it is for adolescents and youth to get out of the house so that they can take on the world. Being cooped up indoors for extended periods affected them in unpredictable ways. One of our pending social issues is the design of cities that offer more opportunities for social connection and engagement for the enjoyment of young people, and not only (digital) spaces that cause tension or encourage screen-addicted youth to view the lives of others. Mere positive thinking or self-help is not enough to counter the harmful effects of individualism. Simply providing more psychologists in primary care health centres is not the solution either. We need fair institutions, with employment and housing policies. Access to housing and its corresponding policies have been seen as a problem for social services, condemning them to the quixotic task of asking beneficiaries to make socio-educational commitments that many are unable to make despite wanting to do so. Social service professionals may feel perplexed when their local public administration offers housing rental assistance to young people through a digital application and access to aid is granted subject to the strict chronological order in which the applications are received, without any other criteria.

The social perspective is also an environmental perspective. We face a great environmental challenge which demands a change in the way we envision society, production, and consumption. The One Health concept reminds us that, far from being independent, we are more interdependent on other living beings, emphasizing the need to move beyond traditional biomedical indicators to manage health effectively.

Health should not be managed via biomedical indicators alone. In brief, the social dimension of health care intervention adds complexity, particularly in societies with diverse moral and cultural perspectives on living, raising children, education, and dying. However, the ethical and civic framework underlying bioethics can serve as an umbrella to shelter, protect and guide every one of us. The state of social services can reveal much about the health of a society. Hospitality, justice, and care are its watchwords; the social and moral aspects that define a community. ///

Bioethics: a look into the future

MEDICINE, FROM THE EYES OF THE PATIENT

Bonaventura Clotet

The COVID-19 pandemic has once again highlighted the importance of two of the basic principles of bioethics: autonomy and justice. Individuals and groups are susceptible to harm or injustice during outbreaks of infectious diseases and that is why it is important to develop plans that address their needs before an outbreak occurs and, when it happens, to ensure that these needs are met.

I have always believed that people are the driving force behind research and medicine. Putting them first is what has pushed me to grow, embark on new projects and make the right decisions in my professional career. Indeed, this idea, which has become one of my mottos, is also one of the goals of bioethics: to conduct biomedical and clinical research on the basis of reasoned thinking, empathy and reflection, whilst ensuring patient safety. It is this principle that compelled me to specialize in the study of infectious diseases more than forty years ago.

THE STUDY OF HIV/AIDS, A NEW CHALLENGE

In my case, it all started when I visited, together with the dermatologist Caterina Mieras, a patient being treated by Dr Jaume Vilaseca at the Vall d'Hebron Hospital who was suffering from skin lesions caused by Kaposi's sarcoma. Little did I realize at the time that the 35-year-old man before me would become Spain's first documented case of AIDS. Even more unexpected was the fact that this disease would become the foundation for one of the most significant research paths of my scientific career. After this patient, many more cases followed. I remember each and every one: the despondent look in their eyes, people consumed by a disease that left them hopeless. We could only offer them quality of life, as we were unable to provide quantity.

The first crisis situation in a hospital you face as a doctor represents a turning point where you either choose to empathize with the person lying in bed in front of you, or to continue with your usual clinical routine without becoming emotionally involved with that person's life or future. In uncertain situations, such as the emergence of a new and untreatable disease like AIDS, bioethics plays a vital role for those of us involved in clinical practice and research. During the HIV/AIDS epidemic, despite the limited options available for treatment, I felt compelled to turn to patients seeking ways to assist them and find a solution. That is why, in 1995, I asked the "la Caixa" Foundation and the Government of Catalonia for the necessary support to create a research laboratory, the IrsiCaixa AIDS Research Institute, which I still direct. Thanks to the dedication of numerous individuals who joined the efforts to study the disease, which was rapidly spreading worldwide, we now understand that it was caused by the human immunodeficiency virus (HIV). This virus was first discovered by the team led by Françoise Barré-Sinoussi and Luc Montaigner in 1983, in Paris.

My initial encounter with bioethics left a lasting impression, and over the course of my career, its significance has only grown. In the field of infectious diseases, bioethics has become an integral part of our profession, allowing us to address ethical concerns. What began as a valuable resource during critical moments has now become part of our daily routines, with research ethicals

Dr Bonaventura Clotet has a PhD in Medicine from the Autonomous University of Barcelona in 1981, focusing his thesis on autoimmune diseases. During his residency at the Vall d'Hebron Hospital that same year, he encountered the first case of HIV/AIDS reported in Spain.

This experience spurred him to dedicate his career to researching and treating this debilitating disease. Dr Clotet subsequently became the head of the HIV Unit at the Germans Trias i Pujol Hospital (1987–2015) and founded the Fundación Lucha contra las Infecciones (1992 – present).

Recognizing the importance of research in advancing treatment for HIV, Dr Clotet established the IrsiCaixa AIDS Research Institute in 1995 with the support of the "la Caixa" Foundation and the Department of Health of the Government of Catalonia. He continues to direct this institute today.

Currently, he also serves as the territorial clinical director of infectious diseases in the Northern Metropolitan Area as part of the Catalan Institute of Health and serves as a scientific advisor for AELIX Therapeutics and AlbaJuna Therapeutics, two spin-offs out of IrsiCaixa.

committees for clinical trials, safeguarding of personal data, and more.

BIOETHICS DURING THE PANDEMIC

As the current director of IrsiCaixa, president of the Fundación Lucha contra las Infecciones, and territorial clinical director of Infectious Diseases in the North Metropolitan Area, I have had to make challenging decisions, especially during the ongoing COVID-19 pandemic. The emergence of this new disease has placed all of us who have devoted our careers to infectious diseases back into a state of uncertainty similar to that experienced in the early days of HIV/AIDS. We have found ourselves immersed in managing a pandemic with significant ethical implications. The COVID-19 pandemic has had an impact on all four traditional principles of bioethics: autonomy, beneficence, non-maleficence, and justice. However, I would like to highlight the impact on two of these principles: autonomy and justice.

At the onset of the COVID-19 pandemic, the rapid spread of the virus led to the imposition of restriction of movement orders, quarantines, and the reduction of social contact, among other measures. The principle of autonomy, which emphasizes an individual's ability to make personal and free decisions, was significantly impacted by these containment measures. While implementing these interventions posed ethical challenges, the evidence suggested that they were necessary to reduce the transmission of the virus and were deemed justifiable to protect the well-being of the community. Nevertheless, the significance of these restrictions could not be ignored.

During the peak of the health emergency, hospitals were overwhelmed, and a clear shortage of resources was evident. This put a tremendous strain on the health care professionals who found themselves forced to make extremely difficult decisions regarding the allocation of limited resources, such as beds, access to oxygen and respirators, medical-surgical interventions, and more. In such extreme situations, how should the allocation of resources be determined? How can we prioritize when resources are limited and cannot reach everyone?

Later on, vaccines changed the trajectory of the pandemic, providing some respite to infectious disease services in hospitals. However, as was the case with HIV treatments, access to vaccines was not equitable across all countries. Addressing this issue is crucial, first, to adhere to the principle of justice by treating all cases equally and to prevent situations of inequality, and second, to bring an end to this disease.

Outbreaks of infectious diseases often result in certain individuals and groups being more vulnerable to harm or injustice. Therefore, it is crucial for political parties and administration officials responsible for responding to epidemics to develop plans that address the needs of these groups before an outbreak occurs. In the event of an outbreak, it is imperative that efforts are made to ensure that these needs are met universally.

During a pandemic situation, it is crucial for medical and scientific personnel to be able to act and make decisions free from political or economic influences. To achieve this, it is necessary to establish committees consisting of representatives from the fields of science, medicine, epidemiology, and others, selected objectively based on their professional merits. In the case of COVID-19, the pressure that was exerted at the beginning and throughout the pandemic did not allow for a fair prioritization of actions.

ENVIRONMENTAL AND ANIMAL HEALTH

Contemporary health care cannot be viewed in isolation, but rather as an interdependent system that encompasses human, environmental, and animal health, as well as global warming and globalization. This concept, known as One Health, is particularly relevant in the context of infectious diseases, where the emergence of new pathogens is closely linked to globalization and global warming. As urban centres expand, they encroach upon the natural habitats of certain wild species, forcing them to occupy areas where they may come into contact with humans and be exposed to pathogens that were previously confined to animal populations. This transmission of diseases from animals to humans is known as zoonosis and accounts for 75% of human infectious diseases. This has led the field of bioethics related to infectious diseases to return to the foundational principles of bioethics that prioritize humanity's survival on earth. bioethics is now regarded as "a call to responsibility for preserving the environment, atmosphere, and biodiversity".

THE DATA AGE

The use of artificial intelligence and big data has emerged as a valuable tool for monitoring, detecting, diagnosing, and treatment of all kind of infectious diseases. However, these technologies present challenges in terms of protecting the privacy of participant data.

> DURING PANDEMIC SITUATIONS,
> IT IS CRUCIAL FOR MEDICAL AND SCIENTIFIC PERSONNEL
> TO BE ABLE TO ACT AND MAKE DECISIONS FREE FROM POLITICAL OR ECONOMIC INFLUENCES

Data collection plays a critical role in identifying positive cases and social contacts during outbreaks of infectious diseases such as COVID-19 or monkeypox. Although data collection is valuable in public health, it must be subject to oversight by a Research Ethics Committee (REC) to ensure technical security and protect privacy. Given the potential for misuse, personal health data is classified as special and requires the highest level of protection. Safeguarding such data is imperative to ensure its invaluable nature is preserved. In the case of infectious diseases, which are often associated with stigma, data protection must be even more stringent. Failure to do so could have profound implications for individuals' freedom and their ability to pursue their life goals.

At IrsiCaixa, many of our studies involve designing algorithms that can identify individuals who are most likely to respond favourably to treatments for infectious diseases. This approach enables us to enhance medical decision-making.

The collaboration of patients in research is crucial, but we must ensure their personal data is protected. Despite the benefits of research, it is important to recognize that it always involves risks for the participants, such as potential breaches of confidentiality, or unforeseeable adverse effects that were not previously known or understood. To ensure that participants are fully informed of the risks and benefits associated with research, it is crucial to list all potential risks in the informed consent document. Yet it is equally important to consider the benefits of research when weighing the decision to participate. Throughout the process, ongoing monitoring, frequent visits, and access to a direct telephone line should be provided to address any doubts or concerns, instilling confidence and security in the participating patient. However, we must ensure that the interests of science, technology, and society should never be prioritized over those of the individual.

NEW TREATMENTS IN CASE OF EMERGENCY

In the case of serious infectious diseases and cancer, the rapid progression of the illness can result in limited treatment options and poor outcomes. In such cases, it is essential to establish strict criteria that outline how individuals may access treatments that have not been commercialized but have demonstrated clear effectiveness. Weighing the urgency of the specific clinical case against the risk of using new treatments that have yet to receive final approval is critical. While these treatments have demonstrated effectiveness, their use requires careful consideration of the potential risks and benefits. ///

Bioethics: a look into the future

THE SCIENCE AND BIOETHICS OF ASSISTED HUMAN REPRODUCTION

Anna Veiga and Clara González

The emergence of new techniques in the field of reproductive medicine is expected to ignite new debates and raise fresh questions. However, there are certain issues that remain unresolved, not due to their technical complexity, but rather their ethical and social implications. Despite this, it is undeniable that assisted reproduction techniques have played a significant role in promoting reproductive freedom.

On 25th July 1978, the world witnessed a remarkable scientific milestone that continues to raise bioethical issues to this day. Louise Brown, the world's first baby conceived through in vitro fertilization (IVF) - or "extracorporeal insemination" as it was then termed - was born in the United Kingdom. Since that historic day, she has been widely known as the first 'test tube baby'. Today, at 44 years of age, Louise Brown has become a mother without the need for further assisted reproduction techniques and is a prominent speaker who travels the world, sharing her personal journey and the significance of being a living scientific landmark.

The success of the English research team paved the way for other countries to replicate their methods. In 1984, six years after the birth of Louise Brown, Spain celebrated its first birth through in vitro fertilization: a girl named Victòria Anna, who was born at the Dexeus Institute in Barcelona.

Since then, it is estimated that over eight million boys and girls have been born worldwide as a result of assisted reproduction techniques. Spain, in particular, has remained at the forefront of this field in Europe. In 2020, the country recorded 127,420 assisted reproduction cycles, resulting in 27,246 births, making it the most active country in Europe in this area. This is a remarkable achievement, surpassing even countries like France and Germany, as reported in 2020 by the Spanish Fertility Society registry.

A FLEXIBLE LAW

This achievement can be attributed, in part, to Spain's early adoption of legislation that regulated the use of assisted human reproduction techniques. Known as Law 35/1988, it was enacted four years after the birth of Victòria Anna and provided legal clarity for both patients and professionals in this field. Some argue that legal regulation promotes social acceptance, which may have contributed to Spain's success. However, despite this legal framework, certain conservative sectors have criticized the use of these techniques since their inception.

For many years, artificial insemination and in vitro fertilization (IVF) have been the main assisted reproduction techniques used to help couples struggling with conception. Artificial insemination involves the insertion of high-quality sperm chosen for their mobility and morphology into the female reproductive tract. These techniques have become more complex over time, with new advancements in the field. In 1978, the use of sperm from a donor was a major milestone in the field of artificial insemination.

Reproductive medicine gradually expanded its reach, offering treatment options to an increasing number of people. In 1992, G. Palermo introduced the procedure of intracytoplasmic sperm injection (ICSI). This innovative technique involves the mechanical introduction of a sperm directly into an oocyte, making it possible for couples in which the male partner has a compromised sperm count or poor sperm mobility to achieve pregnancy. The incorporation of ICSI into health care practice represented a major breakthrough in assisted reproduction and significantly improved outcomes for certain patient groups.

ANONYMITY OR RIGHT TO KNOW?

Currently, gamete donation programmes, including both oocytes and sperm, make up almost half of all assisted reproduction cycles. There has been much debate regarding whether or not children born from donated gametes should be informed about their genetic origins, but the reality is that only a small percentage of couples opt to do so. In 2006, the Bioethics Committee of Catalonia issued a statement asserting the right of every person to know their biological and genetic origins. The committee argued that understanding one's personal history is essential in the development of their identity, regardless of the method of conception. Along these lines, numerous companies have appeared in the United States offering low-cost DNA sequencing tests that make it possible to trace a person's genetic lineage. There have even been those who have found a half-brother whose existence they were unaware of thanks to this widely available tool.

Regarding the anonymity of donors, Spanish law stipulates that all donations must be anonymous unless there is a risk to the life or health of the child born or if it is essential for criminal proceedings. Some countries have lifted the anonymity of donors, citing arguments similar to those found in the Bioethics Committee of Catalonia's document on the right to know one's origins. The advent of genetic testing and the availability of databases have made it increasingly challenging to maintain the anonymity of donors. The trend in Europe is to lift the anonymity of gamete donations, although there is no consensus among professionals and scientific associations.

GENETIC PREVENTION

The Dexeus Institute also witnessed the birth of the first babies in Spain resulting from preimplantation genetic diagnosis (PGD). This technique enables the identification of certain genetic traits of embryos before their transfer to the mother's uterus. In the first case performed in Spain, only female embryos were transferred to prevent the baby from inheriting haemophilia. The mother was a carrier of the disease, putting male embryos at a 50% risk of inheriting it. In contrast, female embryos would, at most, be carriers of the disease but remain unaffected. Recent improvements in clinical genetics and revolutionary DNA sequencing techniques have made it possible to identify mutations in certain genes as the underlying cause of certain diseases. Thanks to these advances, many couples have been able to have children, ensuring the birth of a healthy baby despite a genetic predisposition to certain pathologies. Currently, it is possible to detect whether an embryo carries mutations linked to a wide range of genetic disorders, as well as to determine predisposition to oncological and degenerative diseases. While it is generally deemed acceptable to screen for embryos carrying mutations linked to serious diseases, opinions differ when it comes to embryos carrying less serious diseases or genetic predispositions to conditions that can be prevented or even cured. The Spanish Commission on Assisted Human Reproduction, operating under the Ministry of Health, reviews such cases not medically indicated.

In addition to identifying genetic disorders, preimplantation genetic diagnosis has also been indicated for other issues. For instance, it allows for the evaluation of the number of chromosomes in embryos and the selection of those having normal chromosomal constitution. This technology has proven beneficial for women of advanced maternal age undergoing in vitro fertilization, as well as for other patient groups, improving the overall outcomes of these treatments.

IMPROVED TECHNOLOGY

Assisted reproduction laboratories have undergone significant changes in recent years. Better equipment and embryo culture methods have resulted in a substantial improvement in the performance and outcomes of assisted reproduction techniques. As a result, most fertility centers now follow a single embryo transfer policy, cryopreserving the remaining viable embryos for subsequent attempts. Today, it is possible to evaluate the state of an embryo without having to open the incubator where it is kept, which was unthinkable in the early days of this field.

After many years of research, the vitrification method was established as a highly successful technique for oocyte freezing. This breakthrough represented a new revolution for assisted reproduction laboratories, allowing them to offer a wide range of options in this regard. Reproductive medicine can now provide a solution to social problems: women who wish to postpone motherhood for personal reasons can freeze their oocytes for future use, without the need to involve a third party in their reproductive plans. This allows them to ensure their offspring is genetically related to them. While this option has opened up a range of social possibilities, it has also proven to be quite controversial. In fact, some large American corporations have even promoted and covered the cost of oocyte preservation for their workers to use in the future. These developments raise important questions about the extent to which a woman is freely able to make decisions regarding her reproductive life. For example, to what extent is it truly the woman’s choice to postpone maternity, and, at what point does the use of cryopreserved oocytes become ethically questionable, especially in cases involving women of advanced age? Some may argue that these decisions are

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Clara González was born in Barcelona in 1980, earning a degree in Biology from the Universitat Autònoma de Barcelona and an M.A. in Bioethics and Law from the Universitat de Barcelona. She is a senior embryologist accredited by the European Society of Human Reproduction and Embryology, with 15 years of experience working as a clinical embryologist.

driven by societal pressures rather than individual choice. Nonetheless, cryopreservation has also provided an opportunity for women undergoing gonadotoxic treatments for medical reasons (such as chemotherapy or the use of certain immunosuppressants) to preserve their reproductive options beyond their treatment period. This has enabled them to pursue their reproductive goals after recovering from their illness. The positive impact of cryopreserving oocytes prior to the administration of gonadotoxic drugs has been demonstrated for women requiring cancer treatment, as it offers a future of life and hope.

Oocyte vitrification has also proven to be very useful for egg donation programmes, enabling the creation of oocyte banks. This, combined with genetic testing that identifies mutations in genes that cause serious diseases, has optimized these programmes by allowing the allocation of cohorts of oocytes with sperm that do not share mutations for the same diseases.

AT THE HEART OF THE CONTROVERSY

Surrogacy represents one of the most controversial assisted reproduction techniques, as some have taken advantage of the unfavourable economic conditions of women in certain countries to exploit them through commercial contracts under abusive conditions. The intensity of this debate has led some parliamentary groups to propose legislation regarding uterine surrogacy. While the use of this technique is limited in most European countries, it is more freely available in other parts of the world, leading to so-called fertility tourism where people seek solutions in countries with little or no legislation on surrogacy. In some cases, surrogate mothers have decided at the end of the pregnancy or after delivery to keep the baby. The difference in legislation between countries has led to several dramatic situations, such as the attempt to register children born to a surrogate mother by the couple in the country of origin, where this technique is prohibited.

Uterus transplantation has emerged as an alternative to the controversial option of surrogacy. In northern Europe, a pioneering group achieved the first successful birth through this technique in 2014, and since then, more than forty children have been born this way. Uterus transplantation is typically performed on women who were born without a uterus, with the donor often coming from their close environment. However, the cost of the procedure remains a focus of attention, as the uterus is not considered a vital organ. Additionally, it is important to consider the complexity of the technique and the risks it poses for the donor.

CONSTANT INNOVATION

Scientific teams around the world are actively researching new techniques to further the field of assisted reproduction, with the ultimate goal of implementing these techniques in the laboratories of hospitals and fertility clinics. Some of these techniques include research with human embryos to obtain embryonic stem cells, improve nuclear transfer techniques, obtain oocytes and sperm from pluripotent stem cells, and gene editing in human embryos. These efforts aim to enhance the performance of current techniques and prevent the birth of children affected by genetic disorders. Not everyone agrees that research should be done on human embryos, especially for those who consider that human life begins at the moment of fertilization. At the other end of the spectrum are those who postulate that the foetus should not be considered a person until the moment of birth. There are some laws that seemingly offer more protection for an embryo of just a few cells than an implanted embryo (or foetus), as in the latter case, the pregnancy can be medically terminated.

In recent years, a new approach called ovarian rejuvenation has emerged, which aims to address age-related infertility in women, especially those with dysfunctional organelles in their oocytes. The technique involves replacing the cytoplasm of older women’s oocytes with cytoplasm from the oocytes of younger women. Statistics reveal a trend of decreasing birth rates and later age of childbirth in developed countries. Once a passing trend, delayed maternity among women is now a widespread reality. Yet human biology and physiology have not adapted to these societal changes, and as a result, assisted reproduction techniques serve to mitigate the adverse effects of age on fertility, particularly in women. The use of oocyte donation and cytoplasmic transfer can be an effective treatment option for young women with poor oocyte quality who are struggling to conceive. However, the question arises whether it is ethical to offer these techniques to women who have already gone through menopause and can no longer conceive naturally. Ensuring the well-being of the unborn child should be the top priority in any assisted reproduction treatment, especially in the case of pregnancy in older women. There are certain risks associated with advanced maternal age, such as a higher incidence of genetic abnormalities and other health issues for both the mother and

ENSURING THE WELL-BEING OF THE UNBORN CHILD SHOULD BE THE TOP PRIORITY IN ANY ASSISTED REPRODUCTION TREATMENT, ESPECIALLY IN THE CASE OF PREGNANCY IN OLDER WOMEN child. Therefore, a careful assessment of the potential risks and benefits should be performed before proceeding with any treatment.

The emergence of new techniques in the field of reproductive medicine is expected to ignite new debates and raise fresh questions. However, there are certain issues that remain unresolved, not due to their technical complexity, but rather, their ethical and social implications. One such issue is the selection of the sex of a child without a medical indication, a practice prohibited by some laws yet permitted in certain countries. Although the proportion of male to female births is not exactly 50%, a natural balance does exist. However, opponents of choosing the sex of an embryo for transfer worry that large-scale imbalances could endanger the survival of our species. The argument presented may not be entirely sound as the demand for sex selection is not likely to be substantial enough to cause a significant imbalance, and both male and female sexes are usually selected. However, this may not hold true in countries where discrimination against a particular gender is prevalent, and so it is important that we take into account the cultural and social context when predicting the outcomes of such practices. In addition, we must also consider the ethical implications of alternatives such as interrupting a pregnancy or even resorting to feticide or infanticide in extreme cases, rather than selecting an embryo that is only a few days old. These decisions require careful evaluation and consideration of various factors, including but not limited to cultural, social, ethical, and medical aspects. On the other hand, it would not seem unreasonable that a couple with four boys could choose to have a girl for no other purpose than to balance their family, a practice known as family balancing.

The successful birth of healthy babies from embryos conceived through in vitro fertilization is the result of the dedicated efforts of many scientists, doctors, and embryologists around the world. Initially, these techniques were primarily used to help infertile couples achieve pregnancy.

Infertility is a disease recognized by the World Health Organization, which considers it a “a global health issue that affects millions of people of reproductive age worldwide. Estimates suggest that between 48 million couples and 186 million individuals live with infertility globally”. Furthermore, this number does not account for those who may not be of childbearing age but still experience infertility. Considering these factors, infertility represents a significant potential world market that is comparable in size to the population of Brazil. The significant number of people affected by infertility highlights the potential for commercial exploitation of this condition, which could overshadow the initial goal of providing medical treatment to those patients who are unable to achieve spontaneous pregnancy due to an underlying medical condition.

As stated earlier, reproductive medicine has the potential to offer solutions to social issues, such as the general issue of delayed motherhood. However, it is essential to recognize that all professionals involved in this field have a responsibility to raise awareness and disseminate information regarding the impact of age on human fertility, particularly in women. Governments play an important role in the promotion of a healthy balance between work and maternity/paternity to facilitate childbearing at more favourable ages from a physiological standpoint. Such policies would not only promote the birth of healthy babies but also reduce obstetric and perinatal problems. Moreover, this could benefit society by reducing the public health spending incurred by complications related to deliveries occurring at an advanced maternal age. In addition to the health and economic benefits, promoting childbearing at favourable ages can also help bridge the generational gap between parents and children. It is crucial for scientific societies to communicate this information to the general population and raise awareness about the impact of age on fertility. However, it is also important to respect the autonomy and reproductive freedom of couples and individuals whenever they decide to have children. Like the contraceptive pill did in its time, assisted reproduction techniques have contributed to this reproductive freedom. ///

Bioethics: a look into the future

ADVANCES IN ALZHEIMER'S DISEASE RESEARCH

Mercè Boada

Alzheimer's disease is complex and has biological, clinical and socioeconomic implications. Ethical and legal considerations must therefore be taken into account when improving the approaches and findings of clinical research that is crucial to improving the lives of people with dementia and finding ways to prevent or stop the disease itself.

Neuroscience is a field of study that has garnered immense interest since the 19th century, with Santiago Ramón y Cajal's pioneering observations describing neurons and postulating the neuron's role as the central nervous system's structural and functional unit. Cajal's work contributed to the discovery of Alzheimer's disease (AD), which was first described by Alois Alzheimer in 1907, with a clinical definition based on exclusion.

AD had a significant impact on global public health by the end of the 20th century (1970), making it a "major killer". This spurred research into the etiology and early diagnosis of the disease. Two significant components of AD, the TAU protein and amyloid-beta protein, were identified in 1980, and research aimed at identifying biomarkers present in prodromal AD began in 2000. The complex nature of AD and its exponential growth in the aging population necessitates a research model that encompasses biomedical, ethical, and socio-economic research.

There are four pillars on which the study of AD is based. The first involves understanding the epidemiology of dementia and AD, with a focus on the disease's incidence and prevalence to guide clinical and basic research. The second pillar addresses the disease's pathogenesis, beginning with the cholinergic and synapse hypothesis and pointing to the hippocampal and inferior temporal gyrus's correlation with mild cognitive impairment. Modern hypotheses focus on the molecular discovery of the amyloid beta and TAU proteins, which has marked a turning point in research aimed at developing a cure. The third pillar involves the search for new peripheral biomarkers versus histopathologic diagnosis, with molecular neuroimaging to visualize brain misfolding proteins in vivo and cerebrospinal fluid and blood biomarkers being significant processes. Finally, the fourth pillar is based on genetics and involves the study of the results of millions of data through accurate mathematical systems to configure a genetic constellation that will lead to personalized and accurate medicine. However, there are significant social concerns associated with AD, such as the uncertainty due to a delay in diagnosis and nihilism strongly rooted in health care systems, along with patients who refuse to seek help. AD is complex, with a biological, clinical, and socioeconomic impact, and ethical and legal considerations must be taken into account while improving new approaches and findings.

The future requires a perspective analysis of aging, and research efforts are focused on improving early diagnosis and selecting the best treatment for AD patients to improve their quality of life. The ultimate goal is to find an effective treatment that will make a significant impact on the history of Alzheimer's disease.

ALZHEIMER'S DISEASE AND BIOETHICS

In line with the scientific development and improvement in AD research,

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At European level, she has participated in different projects such as EPAD (European Prevention of Alzheimer's Dementia Consortium), AMYPAD (Amyloid Imaging to Prevent Alzheimer's Disease) and PreDADQoL and is project leader of MOPEAD (Models of Patient Engagement for Alzheimer's Disease).

She has conducted more than 135 international clinical trials on Alzheimer's disease and other dementias. He has published more than 280 scientific articles, 37 book chapters and 12 medical popularization books.

diagnosis and treatment, there are other bioethical considerations related to prevention and new diagnostic tools. Generally speaking, prevention in all its spheres is focused on improving the quality of life, although the limited cognitive function of patients may condition their capacity to report subjective quality of life indicators critical to this domain assessment and surrogate decision-making. Lack of clarity in such assessments may lead to misunderstanding as well as uncertainty and anguish in early diagnosis. During this stage it is important to consider that a label may directly impact perception and the actions taken during the patient's life. Another question may also emerge: how early should we provide a diagnosis? Although symptoms may be present we need to ask ourselves how early should such diagnostic labels be imposed. In other instances patients may not want to know about their predisposition to develop disease or their diagnosis, and although this may limit medical practice this is still their right. The goal should be to promote motivation, accountability, and adoptability, and to share knowledge and skills that improve the well-being of citizens. The importance of ethical and legal considerations in dementia research cannot be overstated. The PRETAD study, a European multicentre study, examines the ethical and legal implications of predicting Alzheimer's disease. This article also highlights ACE's contributions to clinical research and technological innovation in the field of neurodegenerative diseases.

THE IMPROVEMENT OF GENETICS IN ALZHEIMER'S DISEASE

From a genetic point of view, two forms of AD have been recognized: the autosomal dominant form for Early Onset AD, as a result of mutations in the amyloid precursor protein (APP), presenlin-1 and presenilin-2 genes; and the polygenic form, mainly described for Late Onset AD. The heritability of AD is estimated to be between 60% and 80%. This strong genetic component provides an opportunity to determine the pathophysiological processes in AD and to identify new biological features, new prognostic/diagnostic markers and new therapeutic targets through translational genomics. The major genetic risk factor for AD is the ε4 allele of the apolipoprotein E (APOE) gene first identified almost 30 years ago using linkage techniques. Having two copies of the ε4 allele increase the risk of developing AD 8 to 12-fold while having the APOEε2 allele decreases the risk compared to the most common APOEε3 allele.

With the development of genotyping arrays in the early 2000s, genome-wide association studies (GWAS) became possible, leading to the identification of additional genetic risk variants for LOAD. Today, more than 80 genetic risk factors have been associated with LOAD through GWAS of AD case-control datasets. However, much of the underlying heritability remains unexplained. With the advent of next-generation exome and whole genome sequencing, rare genetic variants with large effects on disease risk are coming to light. Further disentangling the genetic constellation of common and rare genetic variations underlying AD can drive our biological insights of the disease and can point toward novel drug targets.

At ACE we have built a large genetic collection with more than 20,000 samples that will help to advance future work in innovative clinical research.

CLINICAL PREDICTORS IN ALZHEIMER'S DISEASE

Increasing life expectancy has led to an ageing population, which has consequently increased the prevalence of AD. AD cases are expected to reach 131 million by 2050, and this increasing prevalence will critically burden economies and health systems in the decades to come. The late diagnosis of AD constitutes a major obstacle to effective disease management. Therefore, improved diagnostic tools and new biomarkers for AD are urgently needed to ensure early diagnosis. Biomarkers are quantifiable molecules or processes that can be related to the biological alterations and/or pharmacological responses to a therapeutic intervention for a specific disease.

An ideal biomarker should be specific, sensitive, predictive, accurate, robust, inexpensive, and ideally non-invasive and measurable in common biological fluids such as serum, saliva and/or urine. For AD, cerebrospinal fluid (CSF) is considered the optimal biological source for biomarker assessment, since its direct contact with the interstitial fluid where the brain is immersed reflects the pathophysiological changes of AD progression in real time. However, many efforts are being made to translate these measurements to plasma.

The clinical course of AD begins with the accumulation of the first senile plaques, composed of extra-neuronal deposits of amyloid-β peptide (Aβ); neurofibrillary tangles, composed of intra-neuronal deposits of hyperphosphorylated tau (pTau); and synaptic dysfunction. These processes start in the preclinical stages, when the manifestation of symptoms is not yet appreciable. Memory and cognitive alterations appear first. Their potential use in the detection of AD in its early stages and the monitoring of disease progression is one of the current challenges in biomarker research. However, more studies are needed to produce sufficient clinical data that can ensure the robustness of findings and facilitate their translation into routine clinical practice.

Our center is conducting a study called Biomarkers in Early-Onset Mild Cognitive Impairment (BIOFACE), which aims to enhance diagnostic accuracy and enable early detection of mild cognitive impairment.

FACEMEMORY®

Facememory® is the first fully self-administered verbal memory test that can be completed on a computer or tablet using voice recognition which offers automated immediate correction. It allows for the early detection of cognitive decline and Alzheimer's disease in the general population. Available in Spanish, Catalan, and English, it is free of charge and can be used by anyone who wants to assess their memory in their native language from anywhere in the world from the comfort of their own home.

Facememory® is a scientifically validated test based on the results obtained in research on the reliability of responses in online tests by the Ace team. Since its launch on 29th May 2021, more than 2,900 people from 40 different countries have used this tool.

More than just an online test, Facememory® provides data that enables our neuropsychology team to continue studying memory and risk factors for developing AD.

In order to identify subgroups of patients based on the progression of the disease over time, our medical psychology program has designed an artificial intelligence project. The following provides a brief overview of this initiative.

SPONTANEOUS LANGUAGE (TARTAGLIA PROJECT)

In the Tartaglia project, 16 healthcare and technology entities are working together to exploit the power of artificial intelligence to solve some of the challenges of medicine and accelerate clinical research in various pathologies (Alzheimer's, prostate cancer, retinopathy), through the analysis of spontaneous speech.
The key to Tartaglia lies in establishing a federated network that fosters collaborative work between various entities, enabling secure sharing of clinical data and convergence of diverse professional profiles such as healthcare professionals, biologists, computer scientists, data scientists, and others. Speech analysis is based on the analysis of conversations or the spoken description of ordinary tasks that are often related to daily life activities. The ACE is the leader of the Alzheimer's research group within the Tartaglia Project, where one of the main objectives is to identify parameters of spoken language that allow the identification of people who are at higher risk for this disease.

PLASMAPHERESIS IN ALZHEIMER'S DISEASE

As we know, AD is a chronic neurodegenerative disease and the most common cause of dementia. It has a complex pathophysiology that is not yet completely understood, where multiple central, systemic, and environmental factors play a key role in disease progression. Understanding the multifactorial nature of AD is paramount to formulate new therapies.

At a cellular level, the two major molecules involved in AD are amyloid-β peptide (Aβ), and tau protein. Maintaining a balance between Aβ production and clearance is essential to preserve brain health as Aβ accumulation will lead to increased oligomer production and neurotoxicity.

Aβ pathology is therefore predominant in the earlier stages of AD and it helps to the progression of the tau-based neurofibrillary pathology that is associated with the clinical manifestations of the later stages of AD.

The pathophysiological process of AD is thought to start many years before clinical disease onset. However, the natural history of asymptomatic biomarker positivity in the preclinical phase toward the subsequent appearance of clinical manifestations remains poorly understood. Even though strong evidence supports the role of Aβ aggregation in initiating AD pathogenesis, to date, a number of Aβ-based therapies appear to be ineffective in modifying the course of the disease once it is symptomatic.

THERAPEUTIC PLASMA EXCHANGE IN NEUROLOGY

Therapeutic plasma exchange (TPE) is a procedure in which blood is passed through a device that separates and removes the plasma from its cellular components. The removed plasma is discarded, and replaced with either a colloid solution (like albumin) or a combination of crystalloid and colloid solutions. TPE has the potential to effectively remove excess of Aβ and proinflammatory mediators. In addition, the pleiotropic properties of albumin could play a key role if used as the replacement fluid in the PE-based therapeutic strategy.

THE ROLE OF ALBUMIN

Human serum albumin is a protein that is primarily synthesized in the liver, and it binds and transports various molecules throughout the body, such as fatty acids, drugs, and proteins. Albumin also acts as an antioxidant and has immunomodulatory properties. It is believed that albumin may help maintain a balance of Aβ levels in the blood and brain, and that changes in this equilibrium may contribute to Alzheimer's disease (AD). The Alzheimer Management By Albumin Replacement (AMBAR) programme uses plasma exchange (PE) with albumin replacement to remove albumin-bound Aβ from plasma and shift Aβ from the brain to the bloodstream. The programme has completed clinical trials in patients with mild-to-moderate AD.

Plasma exchange with albumin replacement in patients with Alzheimer's disease

The AMBAR study showed promising results in this kind of patients using plasma exchange (PE) with albumin replacement to remove

CEREBROSPINAL FLUID IS CONSIDERED THE OPTIMAL BIOLOGICAL SOURCE FOR BIOMARKER ASSESSMENT albumin-bound Aβ from plasma, potentially reducing Aβ brain levels through a peripheral sink hypothesis. Further studies are needed to investigate other mechanisms of action and confirm the efficacy of PE in larger cohorts of patients in the early and intermediate stages of AD. The role of PE with albumin in removing harmful substances in other neurodegenerative diseases, such as Parkinson's disease, should also be explored. The findings from the AMBAR study also warrant investigation of the effects of PE with albumin in patients with mild cognitive impairment and other types of dementia. Overall, more research is needed to turn advances in the understanding of AD's pathophysiology into successful treatments for AD patients.

RESEARCH AND THERAPEUTICS: THE CONTRIBUTIONS OF ACE

Along these lines, the clinical research programme is involved in other projects such as ACE's:

- Healthy Brain Initiative (FACEHBI) which aims to determine the relationship between subjective complaints and AD. This study follows up on clinically healthy patients who percieve memory loss, which involves neurological and neuropsychological assessment, magnetic resonance imaging and the study of blood biomarkers.

- The NORFACE project at the ACE Alzheimer Center Barcelona is focused on examining the connection between cognitive impairment and retinal thickness in patients with Alzheimer's disease (AD). The goal of the project is to establish the use of optical coherence tomography (OCT) as a reliable tool for assessing cognitive impairment and dementia in AD patients. The project aims to provide new insights into the underlying pathology of AD and to identify potential therapeutic targets for the treatment of cognitive decline.

- We are also collaborating with national and international institutions on the AMYPAD (Amyloid Imaging to Prevent Alzheimer Disease) Study, a European multicentre study that aims to investigate the use of amyloid positron emission tomography (PET) imaging as a predictor of cognitive decline in patients with mild cognitive impairment (MCI) or subjective cognitive decline (SCD).

In conclusion, Clinical research is important for understanding dementia and developing new treatment and prevention strategies. It allows researchers to evaluate potential therapies, assess risk factors, and identify early warning signs for earlier diagnosis and intervention. Clinical research is crucial for improving the lives of those with dementia and finding ways to prevent or halt the disease. ///

References:

Díaz, L. A. (1997). *La obra neuro-embriológica de Santiago Ramón y Cajal*. Dynamis, 17(17), 259-279. https://doi.org/10.4321/106117.

Cummings J., Aisen PS., DuBois B., Frölich L., Jack CR Jr., Jones RW. et al (2016). *Drug development a la in Alzheimer's disease: The path to 2025*. Alzheimers Res Ther.

Whitehouse, P. J. (2019). *Ethical issues in early diagnosis and prevention of Alzheimer disease*. Dialogues in Clinical Neuroscience, 21(1), 101-108. https://doi.org/10.31887/dcns.2019.21.1/pwhitehouse

Nichols E., Szoeke CEI., Vollset SE. et al (2019). *Global, regional, and national burden of Alzheimer's disease and other dementias, 1990 - 2016: a systematic analysis for the Global Burden of Disease Study 2016*. Lancet neurology. 18:88-106.

Cummings JL., Isaacson RS., Schmitt FA., Velting DM (2015). *A practical algorithm for managing Alzheimer's disease: what, when, and why?* Annals of Clinical and Translational Neurology. 2(3):307-23.

Boada M., Kiprov D., Anaya F. et al (2022). *Feasibility, safety, and tolerability of two modalities of plasma exchange with albumin replacement to treat elderly patients with Alzheimer's disease in the AMBAR study*. J Clin Apher.

Boada M., Martínez-Lage P., Serrano- Castro P., Costa M., Páez A. (2021). *Therapeutic plasma exchange with albumin: a new approach to treat Alzheimer's disease*. Expert Rev Neurother. 21(8):843-849.

Villeda SA., Plambeck KE., Middeldorp J. et al (2014). *Young blood reverses age-related impairments in cognitive function and synaptic plasticity in mice*. Nat Med. 20(6):659-663.

Boada M., Anaya F., Ortiz P. et al (2017). *Efficacy and safety of plasma exchange with 5% albumin to modify cerebrospinal fluid and plasma amyloid-β concentrations and cognition outcomes in Alzheimer's disease patients: a multicenter, randomized, controlled clinical trial*. J Alzheimer's Dis. 56(1): 129-143.

Boada M., López O., Núñez L. et al (2019). *Plasma exchange for Alzheimer's disease management by albumin replacement (AMBAR) trial: study design and progress*. Alzheimer's Dement Transl Res Clin Interv. 5 (1): 61-69.

Boada M., López OL., Olazarán J. et al (2020). *A randomized, controlled clinical trial of plasma exchange with albumin replacement for Alzheimer's disease: primary results of the AMBAR Study*. Alzheimer's Dement. 16(10): 1412-1425.

Bioethics: a look into the future

ARE WE WITNESSING THE DAWN OF THE POSTHUMAN ERA?

Salvador Macip

Transhumanism allows us to go beyond the possibilities and limitations of biology. For the first time, we can think of acting medically on healthy people, not only to prevent health problems, but also to expand their capacities and qualities. We are entering uncharted territory, as yet unregulated and ethically questionable.

In late 2018, the birth of two girls in China marked a potential turning point in scientific and societal progress, bringing to life an idea that had long been the domain of science fiction. Chinese biophysicist He Jiankui had used the CRISPR/Cas9 molecular editing technique to modify their genome before they were born, deleting a gene in order to reduce their susceptibility to the AIDS virus. This was the first time this technique had been applied to humans, after years of being routinely used in gene editing procedures in a wide range of living organisms in laboratories around the world. While the exact details of this experiment are still not known, it could be said that these girls are the first true posthumans, ushering in a new species of hominid, which some believe could even displace the hegemonic *Homo sapiens.*

THE ERA OF TRANSHUMANISM

Technically speaking, few experts would dispute that the genetic engineering of human embryos represents one of the most significant scientific breakthroughs of the 21st century. The introduction of CRISPR/Cas9 in 2012 marked a critical turning point, as it enabled us to overcome the limitations of existing protocols and push the boundaries of what was previously possible. Since its introduction, the CRISPR/Cas9 technique has undergone continuous refinement, and has now reached a stage where it is possible to edit the DNA of virtually any organism in a relatively simple, inexpensive, and efficient manner. With this powerful tool, we can now easily target, change, replace, and add pieces to a genome, with all the associated consequences. Moreover, it appears that this technique can be easily applied to humans, unlike other gene editing methods, as Dr He's experiment has shown.

As previously noted, the birth of the genetically modified girls in China marked a potentially ground-breaking moment in the development of transhumanism. Until then, the practical applications of this concept had only been explored by researchers. The ability to permanently alter the human genome by editing an individual's genes before their birth is a radical advance that opens doors we had previously only contemplated theoretically. As a philosophical, scientific, and cultural notion, transhumanism seeks to harness the power of science to transcend the limitations and possibilities of biology. Regardless of the technology used, this idea can be approached from a variety of perspectives, ranging from extreme positions that argue we have an obligation to use all the tools at our disposal to improve ourselves as individuals and as a species, to more moderate proposals. Opponents of transhumanism, who express concerns about its potential risks and ethical implications, are often referred to as bioconservatives, who, like transhumanists, may also hold varying degrees of extremism in their views.

AN AGE-OLD CONCEPT

Transhumanism has been around for a long time, predating the

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development of the technology needed to make it a reality. In fact, it could be argued, albeit with some stretching of the definition, that the emergence of modern medicine itself represents the first step towards transhumanism, given that its primary objective is to surpass the biological limitations that dictate the average life expectancy of 30-40 years in humans. However, medicine only represents the tip of the iceberg when it comes to the cultural changes that transhumanism entails. In many ways, humans of the 21st century seem like an entirely different species compared to our Homo sapiens ancestors. Although our genes remain largely unchanged, our capacities have been magnified by scientific, social, and philosophical knowledge that has developed since the early 20th century. Culture has made us smarter, much like the mutations that propelled our ancestors away from the limited brainpower of other hominids such as Neanderthals tens of thousands of years ago. In addition, advancements in our ability to control food and disease have enabled us to become physically superior to our ancestors. It's undeniable that modern humans, on average, are taller, heavier, more intelligent, and longer-lived than our primitive predecessors, which sets us apart in a league of our own.

The most radical form of transhumanism aims to push even further by leveraging our knowledge to surpass all possible limitations, rather than wait for natural selection to slowly shape our genome over thousands of years. This movement seeks to propel humanity to the next stage of evolution, that of the posthuman, using technology in a faster and more deliberate manner. By doing so, any enhancement seen as positive can be applied to make us better than ever before. Of course, the definition of positive and any changes we view as being acceptable are subjective and can vary greatly between cultures or even from one person to another person. This is one of the most controversial aspects of transhumanism, and it will require thorough discussions from a bioethical and social perspective.

It's very likely that some of the proposed enhancements will garner widespread agreement. For example, there is growing research in the field of ageing that could considerably lengthen the average life expectancy. Genetic modifications have already been successfully performed in laboratory animals, including mammals such as mice, that have extended their lifespans. While human ageing is more complex than that of other mammals, the underlying biological mechanisms are similar. Therefore, in theory, we should be able to apply the same principles that have been successfully used before. For instance, it may be possible to eradicate cancer by reinforcing the mechanisms behind cell defence with an additional copy of one or more genes. Similar experiments have already been conducted successfully in mice, and this has also been shown to occur naturally in other species such as elephants.

While some modifications may be considered generally desirable goals, others may serve purely aesthetic purposes with little practical utility in terms of improving the quality of life. Although these modifications may attract the attention of many, objectively speaking, they may be deemed unnecessary. While transhumanists may advocate for unrestricted access to modifications such as these, bioconservatives are likely to see them as a red line that should not be crossed.

The main novelty of transhumanism is that it proposes to improve human beings in every possible way, rather than simply focusing on preventing or curing illnesses, which has been the traditional focus of medicine and science. What's truly innovative yet morally problematic about this is that for the first time, we can envision scenarios in which medical enhancements are provided to healthy individuals, not only to prevent health problems but also to expand their capacities and traits. This approach takes us beyond the traditional scope of medicine, which is centred on disease, and into unknown territory that is not yet adequately regulated or ethically clear.

Given the arguments presented above, the improvements to the human species that transhumanism proposes would generally differ from what natural selection has provided us up to this point. From an evolutionary standpoint, the designation of *better* has no subjective connotations since it specifically refers to traits that enhance our survival and reproduction. Arguably, natural selection has lost its significance for humanity since our survival is no longer as dependent on external factors as it once was. As a result, this selection mechanism may no longer be effective in preventing the perpetuation of genes that make us vulnerable. Transhumanism has the potential to render the impact of evolution on humanity irrelevant.

ETHICAL CHALLENGES

There is little doubt that transhumanism will become a reality, and we can expect to see more and more posthumans in the future. In a hundred years, humans could be dramatically different from what we are today, perhaps even more so than the difference between us and humans who lived a thousand years ago. If the most radical transhumanism becomes the norm, we may have to completely redefine what it means to be human, as we could genetically engineer our offspring to unprecedented extremes. However, before these designer babies become technically feasible, we need to attain a deeper understanding of our genome and develop genetic technologies that pose no danger to humans. The ethical challenges of transhumanism are already emerging as the first genetically modified human beings have already been born. In addition to the girls genetically altered by Dr He, individuals who refer to themselves as cyborgs —people with mechanical implants such as Kevin Warwick or Neil Harbisson— could also be considered posthuman.

If we accept the inevitability of transhumanism, then discussion must turn towards how it should be regulated to avoid potential issues and determine to what extent we want humanity to change. The moral principles of each country, society, time, and individual will make it difficult to define a universal norm that all cultures can agree upon in the long term, which increases the risk of misuse of these technologies somewhere in the world. It's pointless for one country to ban certain genetic editing procedures, for example, if someone can travel to another country with softer laws and have them carried out there.

GIVEN THE INEVITABILITY OF TRANSHUMANISM, THE DISCUSSION SHOULD SHIFT TOWARDS REGULATION TO DETERMINE THE DIRECTION OF HUMAN ENHANCEMENT

Currently, there is a growing consensus that Dr He's experiment, ethically speaking, is difficult to justify, as he used an experimental technology whose consequences we do not yet fully understand to achieve a non-essential goal. Several studies have suggested that CRISPR/Cas9 can cause unintended changes in random regions of the genome, which may result in unforeseen side effects that persist throughout a person's life. Furthermore, the removal or addition of genes in an organism rarely has a discrete and linear effect since all genes play multiple roles and participate in complex functional networks. It's unlikely that Dr He's gene editing will only have the desired effect; with all certainty, there will be other unexpected, perhaps even harmful consequences that are not acceptable to us as a society. Genetic editing of embryos has a far deeper impact than any other genetic modification seen so far, as any unforeseen problem that arises will not only affect the study subjects but also all their descendants for centuries to come, as changes in the genome are inherited from one generation to the next. It should therefore come as no surprise that these experiments have unanimously condemned by the international community.

LATE-ENDING DEBATE

This case has ignited a necessary and long-overdue ethical debate, as it has shown that a challenge that was once purely theoretical has now become a reality. Ideally, this debate should have taken place decades ago since progress towards the genetic modification of embryos has been gradual and predictable. With numerous incremental improvements already signalling that we were heading in this direction, it was crucial to start considering the potential impact of these advancements. If we, as a society, had understood the gravity of the situation and had initiated a discussion involving all relevant parties —including scientists, politicians, philosophers, civil society, and more— it might have been possible to prevent the birth of these genetically modified children.

A complete ban on such techniques, as well as other less radical modifications proposed by transhumanism, may not be the only desirable option. Like many scientific advancements, their ethical implications depend on their applications. If used for medical purposes, they could prevent hereditary diseases or protect us against illnesses such as cancer or Alzheimer's disease, which have a strong genetic component.

The primary danger of indiscriminately authorizing such techniques without a clear medical indication is that arbitrary tendencies may lead to the homogenization of humans in certain ways. One can imagine a scenario where this power is utilized to erase physical signs of ethnic identity, such as skin colour, or the shape of one's nose or eyes. These could be construed as a form of eugenics, a mode of thinking that we should have left behind long ago.

It could be further argued that in its support of the active enhancement of the human genome, transhumanism is nothing more than an attempt to promote a modern and more acceptable form of eugenics, a practice that has existed in one form or another since the beginning of recorded history. Plato proposed selective mating to produce a physically superior class, and the Spartan tradition of eliminating babies deemed unsuitable by the council of elders is well known. The modern version of eugenics originated from the theories of Francis Galton, who developed it in the late 19th century based on his interpretation of Darwinism. Although at first glance it may seem like a valid objective in line with nature, historical uses of eugenic theories have always involved discrimination and violations of the basic rights of certain groups arbitrarily deemed inferior. The most significant negative impact of eugenic theories was perhaps the adoption and perversion of these ideas by the Nazis, who used them to justify many of their crimes against humanity.

There is a fear that transhumanism may lead us to repeat past mistakes with even more severe consequences, but it could also be argued that some degree of eugenics has already been incorporated into our practices without much objection. In many advanced countries, routine or optional tests are conducted on embryos to detect genetic alterations like Down syndrome, with the intention of terminating the pregnancy if such defects are identified.

The concept of having children *à la carte* would greatly magnify the eugenic capacity of parents to decide their children's future. The definition of defect could be extended indefinitely, and the consequences would have an impact on several generations to come. Some argue that the ability to select the genetic traits of one's children is already a parental prerogative. After all, parents already make important decisions that impact their children's future, such as choosing their schools, cultural experiences, place of residence, and dietary habits. These decisions have a lasting impact, not only on the child but also on future generations. Transhumanism merely amplifies this effect; it does not introduce a fundamentally new ethical problem.

HUMANS AND POSTHUMANS

Before assessing the impact of transhumanism on society, we should first consider what a society with both enhanced humans and traditional individuals would look like. One concern is that the presence of posthumans could exacerbate the existing demographic challenges seen in many developed countries, due to the likelihood of increased longevity. The challenge of providing pensions to an ageing society would be compounded if the majority of the population lived beyond the age of 90 or 100 in good health. At what age should the State push back retirement in order to avoid an excessive economic burden? Would individuals be willing to work until they are 80 years old, for instance? Moreover, if this became a reality, how would it affect the labour market? Could posthumans potentially create a barrier that would prevent new generations from entering the workforce?

Another important issue to consider is the limited availability of human enhancement technologies. Initially, only those who could afford it, either through personal means or public health systems, would benefit from these enhancements. This could potentially widen the gap between rich and poor countries, as has been the case with many medical advances throughout history, such as early antibiotics, cancer drugs, or antiretroviral treatments for AIDS. However, it should be noted that limited availability has never prevented at least some portion of the population from receiving life-saving medical treatments. It can be argued that this approach is fairer as long as the benefits eventually reach everyone in a reasonable amount of time.

A libertarian approach to transhumanism that leaves all decisions solely in the hands of the patient may run the risk of creating a society with two distinct levels, where economic privilege —both personal and national— determines which *species* one belongs to: one without diseases and perhaps with a lifespan exceeding a century, and another still struggling with infections and diseases that result in an average life expectancy of less than 50 years. This situation may not be entirely new, as similar disparities already exist between the average citizen in Western countries and those in some parts of Africa, with the most extreme differences being an average life expectancy of 84.3 years in Japan compared to only 50.7 years in Lesotho.

It is possible that a less disruptive social transition may be feasible, although it would require careful consideration and implementation to ensure that it is executed with appropriate guarantees. Historical evidence suggests that, at least until the early 21st century, our society has made significant progress in terms of improving our knowledge, quality of life, and equity. These achievements are difficult to quantify, but there are certain indicators such as life expectancy, educational attainment, and purchasing power that could help us even though at times they can be seen as being subjective in nature. However, we should also acknowledge that progress has been uneven and that the situation in many regions around the world is still quite different.

While progress has historically contributed to reducing social inequalities, it is not the only path for modern societies to keep on advancing. In recent years, we have witnessed quite the opposite, with many countries seeing a worrying resurgence of populism, fascism, and totalitarianism, as well as a rise in xenophobia and male chauvinism. These developments illustrate that progress towards a more just society is, unfortunately, not necessarily a linear process but one subject to setbacks and obstacles.

It is therefore evident that technical and scientific progress does not guarantee immediate social improvement. While science has given us vaccines, antibiotics, and longer life expectancies, along with many other positive developments, it is not clear what the future will hold. Recent advances, particularly in the field of genetics, suggest that the era of scientific marvels is only just beginning.

Transhumanism has the potential to bring about significant changes, both positive and negative, and it will be necessary to find ways to integrate them into society. Will we be able to harness the power of transhumanism to continue moving towards a fairer world for as many people as possible? Answering this question will require a deep and thoughtful ethical and social debate. ///

Bioethics: a look into the future

NEUROETHICS AS AN ETHICS OF TECHNOLOGY: THE IMPERATIVE TO MOVE FROM RIGHTS TO CAPABILITIES

Joseph J. Fins

The Fundació Víctor Grífols i Lucas and neuroethics are of the same vintage. The former was founded in 1998 and most historians date the birth of neuroethics to a conference held in San Francisco in 2002. So it could be said that the foundation and this emergent field are contemporaries, sharing a common time of origin and context. In this contribution I will take a more modest course and speak of the evolution of neuroethics over the past two decades. And by looking back I will speculate about the future of this field and its prospects.

Most origin stories begin with a myth and neuroethics is no exception. The myth is that neuroethics originated at that conference sponsored by the Dana Foundation in San Francisco in 2002 and that William Safire, a former speech writer for President Nixon, *New York Times* columnist, and wordsmith, coined the phrase.

Even though others like the late neurologist Ronald Cranford and psychiatrist and neuroscientist, Anneliese Pontius may have originated the term —a point that Safire later acknowledged in 2005— Safire helped to mold neuroethics in the public imagination and direct academic work for decades to come. He wrote several opinion pieces for *The New York Times* about neuroethics and became an early champion of the field, ultimately becoming Chairman of the Dana Foundation and making neuroscience a priority.

His vision of neuroethics, as articulated at the Dana meeting in San Francisco, defined the emergent field as the "examination of what is right and wrong, good and bad about the treatment of, perfection of, or unwelcome invasion of and worrisome manipulation of the human brain". His vision of neuroethics was one of concern, suspicion, and worry. It was not an ethics about the therapeutic possibilities of neuroscience and what it might achieve. Instead it had a dystopian feel to it, a concern about technology run amok, leaving society more endangered and at risk. Instead of viewing science as promoting human flourishing, the manipulation of the human brain would be worrisome and lead to unwelcome invasion.

When Safire wrote his definition there were other visions for neuroethics. Cranford and his fellow neurologist, James L. Bernat of Darmouth Medical School, sought to articulate a neuroethics from the bottom up, from the experiences of the clinic and the ethical dilemmas encountered in practice, attempting as Bernat wrote, to make connections between clinical ethics and clinical neurology. Previously, medical luminaries like the physician William Osler and the neurosurgeon Wilder Penfield wrote about ethics in neurology and neurosurgery even though it had yet to be designated with the more modern moniker of neuroethics.

Alas, neither that historical legacy nor a more clincial vision of neuroethics prevailed. Instead of an ethics of neuroscience and neuropractice, early work in neuroethics strayed from the clinic. Commentators speculated about the mischief that neuroscience might do one day, creating science fiction scenarios that could imperil one's cognitive liberty by technologies that still don't exist. They also wrote about the neuroscience of ethics, that is the neuroscience underlying ethical and unethical behaviour.

So, *in lieu of* an ethics of neuroscience (and clinical practice), the excitement was on what Borges might call *ficciones* or the use of neuroscience to explain the depths of human complexity. Instead of studying the ethics of neuroscience which would have grounded neuroethics in the clinic, and efforts to treat and ameliorate neuropsychiatric conditions, early neuroethics pioneers sought an inverse construction: they pursued the neuroscience of ethics. That is, what could neuroscience say about ethical —or unethical— behaviour.

Although the brain is a complex collection of circuits that we are only begining to untangle, those early days led to grand theories associating hormones like oxytocin with trust, and perhaps even love. While many neuroethics enthusiasts spilled a lot of ink on such correlations, serious students of the brain viewed such explanatory models as the equivalent of modern-day phrenology. More sober commentators turned to the sonnets of Shakespeare or the love poetry of Pablo Neruda for mediations on the human heart, if not the human brain. But no matter, the early days of neuroethics were dominated by both technophobia and rather simplistic theories which outpaced extant science.

NEUROETHICS, TECHNOLOGY & THE CLINICAL IMPERATIVE

In my work, I have sought to articulate a different vision for neuroethics, one which has been directed to the pressing needs of patients and families touched by neuropsychiatric illness or brain injury. I have always felt that I did not need to create hypotheticals to create ethical challenges: the world of clinical practice and neuroscience research present real problems that are stranger than fiction and even more relevant. At the core of these ethical considerations are questions posed and answered by emerging neuro-technologies. Indeed, I have postulated that “neuroethics is an ethics of technology”. Brain based technologies can create ethical challenges and also help to respond to them. In this dialectic, these technologies can expand our ethical horizons.

Let me suggest the example of what has been described as cognitive motor dissociation, a state in which a patient does not demonstrate evidence of awareness at the bedside but responds to volitional commands as seen on functional magnetic resonance imaging of the brain.

The scientific paradigm looks like this: A patient who is thought to be in the vegetative state —a state devoid of consciousness in which the eyes are open but there is no evidence of awareness of self, others, or the environment— is placed into a brain scanner and asked to *imagine* playing tennis or walking around their house. When they do the former task, the motor strip which would normally be associated with the queried behaviour is activated. When they do the later, navigational areas in parietal and occipital lobes are similarly activated.

Here the technology creates an ethical quandry. A patient formally

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thought to be devoid of consciousness is now revealed by technology to in fact be conscious. Unlike a passive response to noise, or even one's name, a subject in this study design has to hear, understand, and act upon the command in order to imagine playing tennis or walking about one's house. This three-step process is volitional and is highly suggestive of a sentient entity processing language and responding to it.

For a patient without behavioural output this evidence of cognitive motor dissociation is a profound game changer. For example, a clinician or family must now consider what one says at the bedside lest one's words might be heard and understood albeit at some level. It compels us to wonder if the person, feels lonely or isolated, missing human companionship.

Cognitive motor dissociation should also engender curiousity. If a patient previously thought to be vegetative is now found to be able to process language what else might they be able to do? We know, for example, that a patient who has intact neural networks may be able to pereceive pain, whereas a patient in the vegetative state can not. This suggests the need for vigiliance about pain and symptom management in patients with cognitive motor dissociation.

NEUROTECHNOLOGIES ADVANCEMENTS

These observations, and ethical realizations, are driven by a newfound ability to understand the injured brain through advances in neurotechnologies. Without functional neuroimaging, we would never know that patients without behavioural evidence of sentience could in fact be conscious. And with this knowledge comes new ethical responsibilities.

In previous writings, I have drawn an analogy to genetics to better capture the clinical and ethical magnitude of cognitive motor dissociation. Genetics has taught us that not all phenotypes (appearances) are the same. We need only recall Gregor Mendel's pea garden to appreciate that some of the plants that appeared the same had distinct underlying genetics. While the implication of these differences would be seen in subsequent generations of inheritance, the key point was that the same phenotype did not always equate with the same underlying genotype.

What is true for genetics is equally important in neuropsychiatric disorders. The same behavioural phenotypes —that which is observed at the bedside— may have distinct underlying circuitry. In the case of brain injury a patient may *appear* to be in the vegetative state and devoid of consciousness and still demonstrate circuits evidencing a response to volitional command when queried in a functional magnetic resonance imaging scan. This discordance between what is observed, and a person's underlying neurophysiology is directly akin to the classic distinction between genotype and phenotype. Although some distinguished scholars like the Scottish neurosurgeon Bryan Jennett and the American neurologist Fred Plum (who was my teacher) entertained the possibility of consciousness *without* behavioural manifestations, in their landmark 1972 *Lancet* paper describing the vegetative state, it wasn't until the advent of functional neuroimaging that we actually had proof that cognitive motor dissociation with covert consciousness could exist.

The ruminations of Jennett and Plum, implied in the logic of their seminal paper, became concretized because of technology that became available decades after they first wrote in *The Lance*t. And that is why I return to the refrain that neuroethics is an ethics of technology. In the unmasking of cognitive motor dissociation, technology diagnostically reveals a problem that previously, before the advent of new technologies, we did not know existed.

But technology is more than just diagnostic. It can also intervene. It can close the circle and *respond* to novel problems exposed by technological advance. If we return to the question of cognitive motor dissociation, we encounter a patient who is covertly conscious but unable to communicate and give voice to his or her consciousness. This is important because because voice becomes a way to represent one's consciousness to others. Given this, reconstituting voice in a person with covert consciousness becomes an ethical mandate. It is how to demonstrate one's presence and to foster community by reestablishing links with others that were severed by brain injury.

NEUROETHICS & DISABILITY RIGHTS

This last point about communication and community touches the relationship of disability rights, neuroethics, and neuroscience. This is a central theme in my book *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness* (Cambridge University Press, 2015). The possibility that technology could foster societal reintegration by restoring functional communication speaks to the normative and legal mandate inherent in the Americans with Disabilities Act and the UN Convention on the Rights of Persons with Disabilities. These legal frameworks both call for the maximal integration of people with disabilities into society.

For a person with a motoric disability this is achieved by making streets and mass transit accessible so that individuals can get from here to there in a wheelchair. For a person with a disorder of consciousness, societal reintegration depends upon the reestablishment of communication. Here we see the connection between communication and community, words which are cognates.

Societal reintegration has been made possible with novel technologies like deep brain stimulation in the minimally conscious state as my colleagues and I demonstrated in a paper published in *Nature* in 2007. A research participant who could not talk, could sometimes move his eyes in response to a command, and who could not eat by mouth received bilateral thalamic stimulation in an NIH funded clinical study. With stimulation he was able to say six- or seven-word sentences, recite the first 16 words of the American Pledge of Allegiance, and tell his mother he loved her. He could maintain his secretions and eat by mouth for the first time in six years, go shopping with his mother, and voice a preference about clothing he wanted her to purchase.

With the stimulator he was brought back into the nexus of his family. His covert consciousness was given voice through neuromodulation. He regained his ability to express a preference through what I have previously described as *agency ex machina* through the electrical stimulation of the brain.

In this way restorative technology responds to the imperatives uncovered by an awareness of covert consciousness. This completes a virtuous cycle of scientific advance that both engenders new needs and prompts an instrumental response. This cycle of innovation is at the heart of translational neuroethics. It links scientific discovery with a normative imperative to give voice to minds that appear silent but may have much to say.

NEURORIGHTS MISCONSTRUED

One would think that identifying covert consciousness and then working to develop technologies that could give voice to those who had been silenced by injury would be considered a good thing. I certainly did, and do. But there is a new threatening specter on the horizon flying under the banner of neurorights that could quell such advances and delay progress. This worries me greatly.

As I recently delineated in a paper entitled, *The Unintended Consequences of Chile's Neurorights Constitutional Reform: Moving beyond Negative Rights to Capabilities* and published in *Neuroethics*, I am deeply concerned about the emergent *neurorights* movement epitomized by recent Chile's constitutional reform movement. That effort, which failed in a plebiscite in September 2022, is nonetheless worthy of commentary because it heralds a neurorights framework which could be antithetical to progress in the neurosciences and could adversely affect those whose neuropsychiatric conditions

RESTORATIVE TECHNOLOGY RESPONDS TO THE IMPERATIVES UNCOVERED BY AN AWARENESS OF COVERT CONSCIOUSNESS might be ameliorated by advances neuroscience.

The Chilean constitutional proposal included an amendment that spoke to protecting an individual's cognitive liberty and safeguarding one's physical and mental integrity. With vague language that would certainly would have been parsed endlessly in litigation and bioethical debate, the constitutional amendment would have had a chilling effect on the care of patients with covert consciousness. The details are beyond this brief essay, and I urge readers to consult my fuller treatment in the *Neuroethics* article. Suffice it to say, the Chilean vision of neurorights was monovalent, focused on negative rights at the expense of correlative positive rights. Instead of speaking of both negative and positive rights its focus was on a slew of prohibitions, namely the right to be left alone and to have one's cognitive liberty secured. Regrettably the Chilean legal regime failed to apprehend that negative rights must coexist and harmonize with positive rights, in this case rights that can restore health and promote abilities, sometimes by breaching negative rights.

This becomes evident if we return to the example of the identification and amelioration of covert consciousness. It quickly becomes apparent that identifying covert consciousness is problematic because neuroimaging to identify cognitive motor dissociation must breach the mental integrity of the patient to see whether (or not) an individual can follow volitional commands. This is further complicated by the fact that this exploration must be done, by necessity, without a person's autonomous consent. (If an individual could consent, their consciousness would not be in doubt.) Restoration of voice via an invasive deep brain stimulator would be even more challenging under the prohibitions that were proposed in the Chilean constitution, further curtailing the therapeutic possibilities of neuromodulation.

NEUROETHICS AND THE PROMOTION OF CAPABILITIES

In the coming years we need to be especially wary of ill-informed *neurorights* initiatives like those that informed the Chilean effort at constitutional reform. While neurorights are important they need to be thought through carefully and with prudence and proportionality. The Chilean prohibitions, intended to be protective, are however not without their own *negative* consequences. Unchecked, they could preclude key diagnostic and therapeutic interventions that could be life-altering for a vulnerable population that has been historically at risk for neglect and marginalization. This one example of covert consciousness —there are many other neuropsychiatric conditions that could be cited— reveals the need for a healthy ecosystem where negative and positive rights coexist in homeostasis.

It is important that neuroethics is clear-eyed about the centrality of technology to its epistemology and that we appreciate the importance of emerging technologies to individuals with neuropsychiatric disorders. Their needs will be best be met when these emerging technologies are used to advance human capabilities that promote human flourishing as articulated by the philosopher, Martha Nussbaum and the Nobel Prize winning economist, Amartya Sen. While this is a high bar to achieve, such aspirations are worthy of the ever-growing potential of neuro-technology to make an instrumental difference for brain and mind. ///

References:

Fins JJ. (2008). *A Leg to Stand On: Sir William Osler and Wilder Penfield's "Neuroethics"*. American Journal of Bioethics. 8(1): 37-46.

Fins, JJ. (2011b). *Neuroethics and the Lure of Technology*. Oxford University Press eBooks. https://doi.org/10.1093/oxfordhb/9780199570706.013.0195. Pages 895-908.

Fins JJ. (2014). *Trastornos de Conciencia y Los Derechos Humanos: Una Nueva Frontera Ética y Científica*. Solemne Sesión de Toma de Posesión como Académico de Honor del Dr. Joseph J. Fins. Con Laudatio del Excmo. Sr. D. Diego Gracia Guillén. Tomo CXXXI. Cuaderno Segundo, e 631- 667.

Fins JJ. and Schiff ND. (2016). *In Search of Silent Minds*. Scientific American Mind. Pages 44-51.

Fins JJ. (2015). *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness*. Cambridge University Press.

Fins JJ. (2017). *Towards a Pragmatic Neuroethics in Theory and Practice. In The Debate about Neuroethics: Perspectives on the Field's Development, Focus, and Future*. Racine E. y Aspler J. Editors. Pages 45-65.

Fins JJ. (2019). *A Once and Future Clinical Neuroethics: A History of what was and what might be*. Journal of Clinical Ethics. 30(1):27-34.

Fins JJ. (2022). *The Unintended Consequences of Chile's Neurorights Constitutional Reform: Moving beyond Negative Rights to Capabilities*. Neuroethics. 15:26. DOI: 10.1007/s12152-022-09504-z

Bioethics: a look into the future

GENOMICS AND ETHICS

Chris Willmott

I am delighted and honoured to join in the celebration of this landmark anniversary in the story of the Víctor Grífols i Lucas Foundation. Some of the most exciting developments in biomedicine during the past 25 years concern our ability to sequence the complete genome of humans (as well as other species) and the applications that stem from that capacity. In this chapter, I am going to review some of those uses and draw attention to potential ethical issues associated with the exploitation of this data.

Back in 1998, when the Grifols Foundation was established, the official human genome project (HGP) to capture the full genetic sequence of humans was already well under way. Interest in this ambitious and expensive project to lay out in order all three billion letters in the *handbook of mankind* had gained traction from the mid-1980s, and the co-ordinated work of the International Human Genome Sequencing Consortium had begun in earnest in 1990. The year 1998, however, has significance in the rise of genomics for two important reasons. Firstly, it was the year that those official partners implemented the so-called Bermuda Principles in which they pledged to make as much of the sequenced DNA data freely available as quickly as possible after it had been determined. This openness represented a paradigm shift, in stark contrast to some of the original pitches for the work, where profits from biotechnological spin-offs were dangled in front of potential investors. Secondly, 1998 was the year that Celera Genomics, a rival to the official HGP, was established. Under the leadership of Craig Venter, Celera initially proposed a profit-driven approach, with access to their data offered on a pay-per-view model (although this too was subsequently liberalized).

Celera promised, and delivered, DNA sequencing faster and more cheaply than had been the case up to that point. This was, in part, derived from the fact that they could exploit the existing mapping carried out by the main HGP as a scaffold in which to fit their data (a bit like having their rivals prepare the picture on the lid of the box allowing them to solve the jigsaw puzzle more quickly). More significantly, however, they offered a radically streamlined method for the sequencing itself. They dispensed with the costly and time-consuming steps of archiving human DNA in bite-size genetic cassettes, stored within bacteria. Instead, they employed a “whole-genome shotgun sequencing” in which they essentially smashed all of the chromosomes into bits around 500 bp (ie 500 letters) in length, which they sequenced directly.

Initially there were significant tensions between the two factions. However, an uneasy truce was called and a deal was brokered in which they both published their draft results on the same day (in 2001). The corrected versions were published in 2003 (though for technical reasons this was still only 92% of the whole. The full sequence, including the tricky bits, not completed until April 2022).

The new Celera approach had transformed sequencing. However, even this cheaper and quicker methodology would still have struggled to deliver some of the health benefits that had been promised as justification for the vast expenditure poured into this big science project. This work, taking many years, at the cost of hundreds of millions (for the Celera approach) even billions of dollars (for the official HGP) had succeeded in producing a reference copy of the full human genome, but it was derived from only a handful of individuals (only around a dozen, across both projects). Of course, the interesting aspects of genomics for us as individuals, the factors that inform both our health risks and our family relatedness, are our distinctives. It has been estimated that for each of us, our DNA deviates from the reference genome by about four million letters. The key benefits of genomic medicine are the capacity to offer personalized medicine, diagnosis and treatments tailored to the specific needs of a patient. These need to be made available in a matter of hours or at most days, at a fraction of the previous costs. For the full potential of this work to be unleashed there would need to be a fundamental change in the way that genomics was done.

Those essential technological advances have now been delivered. Today, DNA can be sequenced using a variety of methods, sometimes grouped under the umbrella term Next-Generation Sequencing, which are fundamentally different to the techniques used for completion of the HGP. Here is not the place to go into the exact details, but the key is that thousands, often millions, of tiny sequencing reactions are set off in parallel. By 2010, it was already estimated that sequencing was 50,000 times faster than it had been in 2000, and in 2022 a human genome was completely sequenced in five hours.

Similarly, the costs have also plummeted. From hundreds of millions or even billions of dollars per human genome, it is now feasible to get a read-out of someone’s whole DNA sequence for a few hundred dollars. These advances combined have opened the door to the post-genomic era – a world of radical opportunities that match and then far exceed the original promise of the HGP. In this next section, I intend to give a swift overview of some of those diverse applications, before drilling down more closely into three of them.

APPLICATIONS OF GENOMICS

Beginning away from specifically human or medical applications, it is now feasible to revisit ideas of the relatedness of species by examining their DNA rather than their physical features. This phylogenetic approach has led to radical rethinking about taxonomy.

By looking at the genetic differences between species, we can also gather very useful clues about the potential function of particular genes. For example, in one study, researchers took the apparently unlikely step of comparing the human genome (which includes code for hair-like structures called cilia), with the genome of a single cell organism called *Chlamydomonas* (which has similar hair-like flagella) and the plant *Arabidopsis* (which has neither). By looking for genes that were present in both humans and *Chlamydomonas*, but not in *Arabidopsis*, they were able to radically shorten the list of potential genes responsible for a cilia-related disease.

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Other comparisons might look at the genomes of a bacterial species which remains susceptible to a given antibiotic and another from the same species which has developed resistance to that drug. By doing so, they can gain insights into the molecular basis of the medicine's loss of efficacy against that organism (and potentially identify ways to overcome the problem). Similarly, we have all seen the ways in real-time sequencing of their genome gave valuable insight into the evolution and spread of the Sars-CoV-2 virus variants in the COVID-19 pandemic (albeit by slightly different methods, since the virus has an RNA genome).

METAGENOMICS

Elsewhere, by trawling an environment for traces of DNA, it can be possible to identify the species living in that habitat, even if you have not seen them. Craig Venter, who we encountered previously in the context of Celera's rival approach to the HGP, famously set sail around the world in his yacht *Sorcerer II* capturing onto filters the DNA from microbes in the oceans he passed through, in order to map the occurrence of known species and give hints of previously unknown organisms. Aside from the inherent curiosity about our world, some of these species might ultimately prove to be useful sources of new medicinal drugs.

Transfer this kind of genomic approach to the human gut, and we are back onto applications of direct medical benefit. There is growing recognition of the impact of the microbiome, species of bacterial and viruses living in our intestines, on our general health. Previous attempts to identify these organisms often floundered because scientists could not work out conditions to grow them in their laboratories. Now a *metagenomic* approach can be used, in which all of the DNA in the gut is sampled simultaneously. This complicated mixture won't easily yield detailed analysis of the genome of any one organism, but by looking at a particular gene that is known to be constant within any given species, but different between species, you can at least identify which bacteria are present.

Finally, let us look in details at three applications of genomics – personalized medicine, whole genome sequencing of newborns, and the rise in user-initiated or direct-to-consumer (DTC) genetic testing. As well as surveying the potential of these approaches, we will also consider the ethical issues that they raise.

DIPPING INTO YOUR DNA RECORDS FROM YOUR OWN HOME

For most people, the first place they are likely to encounter the power of contemporary genomics is in the form of a genetic test they can conduct at home. By 2020, it was estimated that over 30 million people had already taken a test of this kind. Some will have bought them for themselves, most likely out of curiosity about their heritage (the company Ancestry had delivered about half of the tests done at that point), although some may have had medical motives. Others will have had a test bought for them, maybe on the promise of knowing what percentage Viking they would turn out to be.

The ease of access to such tests belies the significance that the results might hold. Whilst knowledge of our genes is potentially empowering, for example if it was to reveal a previously undiagnosed medical condition where treatment was possible, there are a number of significant issues that might arise. The most well-known hazard comes when there is a revelation that someone is not, in fact, biologically related to one or both of the people they have considered to be their natural parents.

On the flipside, the ability to connect with genetic relatives is one of the attractions of home genetic tests – for example, adoptees and those who know that their biological father was a sperm donor are able to forge networks of half-siblings. Others too are looking to make identification via these databases. The arrest and unmasking of Joseph DeAngelo as the *Golden State Killer*, responsible for a series of rapes and murders in the 1970s, is the best known example of police screening genomic archives to assist in solving crimes, but this is becoming a routine aspect of inquiries.

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WHO'S RIFLING THROUGH YOUR GENES?

This raises further concerns about who has access to the genetic information users of DTC sites are handing over to the companies. As we have discussed, the expense of testing has plummeted. However, the fact that some services are offering tests for lower prices that it costs to conduct and process the results ought to be a warning that they are recouping their expenses via other means, for example selling your data to third parties. Add to this the possibility of company buy-outs or of data breaches and you reach a situation where it would be best for users of any DTC service to assume that their genetic information is now openly available to other interested party. Are clients sufficiently aware of this when they sign over their consent?

Additionally, there can be questions about the accuracy of results. Mistakes in sequencing reactions are inevitable. For this reason, industry standards see regions re-sequenced at least 30 times to guard against such errors, and frequently there are 100 re-readings of the DNA to make sure the report is correct. Companies offering sequencing at the lower end of budgets are likely saving costs by only doing a minimal number or re-screenings. This heightens the possibility of results being wrong, either false positive or false negative.

This risk is compounded by the fact that many DTC services still rely on older microarray technologies, where a series of DNA sequences are placed on a *gene chip*. Importantly, this approach involves pre-selection of the mutations being investigated (rather than WGS, where you see what emerges organically from the data). There is growing awareness that uneven distribution of ancestral backgrounds (genomes of Hispanic and African origin are notably under-represented) causes bias in the databases, and may mean important mutations relevant to particular populations are missed simply because the microarray is not set up to look for them.

All of which raises a final concern about DTC services, the lack of genetic counselling available to those who receive genetic information from these companies. What is the mutation is real, but the consequence of that change are not actionable, i.e. there is nothing we can do about this revelation, or will be late onset and irrelevant for many years? Talking people through the interpretation of their results carries an inevitable financial cost, and so counselling is not routinely offered to customers. This can cause them to be anxious and confused. It may leave them turning to more formal health providers (such as the NHS in the UK), passing the burden to the latter.

STARTING THEM EARLY

This leads us into more overtly medical territory, where the roll out of WGS for all newborn babies is actively being considered. Testing in the form of a small blood test, around five days after birth, is already routine in the USA and Europe. However, these only report on fewer than a dozen conditions, all of which are both significantly detrimental if untreated and where knowledge that the child has the fault can facilitate appropriate intervention. Collecting the full genomic information from a baby would be a very different prospect.

Expansion of screening in this way would shine an early spotlight on a far broader range of conditions including rare diseases which might not otherwise be identified for many years. In theory it creates the possibility to produce a genetic passport which the individual could make available to their doctors throughout their lifetime. Proponents are also overt about the research benefits for wider society that would be facilitated by such a systematic collection of data.

Many of the potential risks are the same as we have already seen for DTC testing. These include paternity issues, and concerns about who will have access to the information, both now and in the future. As a state-run scheme there is the added worry that a future dictatorship might abuse the data to victimize a subsection of the population.

There are additional issues in regard to consent. Clearly the infant cannot be asked to give permission for their own checks, and the parents are the obvious proxy. Questions have already been raised about how much parents understand the existing heel-prick tests, since consent is often taken by a midwife as part of barrage of questions at the point where they are somewhat distracted by the exertions of the birth and excitement about their new arrival. And what happens if the parents disagree? What is the default position? Who has the casting vote? What if the child, when they become old enough to offer their own views, wishes to remove their genetic records from the database —will this be feasible?

Some results emerging from newborn screening might be of instant importance, others might only have relevance later in life. Do the parents get informed about these, when it might negatively influence their bonding with the child throughout the latter's whole life? What if that information only had significance so far into the future that the parents might already be dead? And what about the fruits of future research? If gleaning more information about the genetic basis of disease is one of the stated benefits of neonatal screening, then it is probable that some results will gain greater relevance than is initially understood. Would there be a commitment to update everyone as soon as relevant findings are discovered? It is highly likely that emerging significance will relate to so-called polygenic risks where the interaction of multiple genes, combined with environmental influences, rather than to Monogenic disorders where mutation in only one gene is the determining factor. Since lifestyle choices might well be part of the mix, surely an individual needs to know their status as soon as possible so they can make any necessary changes, e.g. to their diet. However, this would be an enormous logistical and financial undertaking, so perhaps a scheduled update every few years is more realistic.

MAKING PERSONALIZED MEDICINE

If discussion about the pros and cons of newborn screening remains slightly future-focused, let us conclude with one application of genomics that has definitely arrived. In various specialisms, the promise of targeted treatment, tailored to the underlying genetic cause with the specific patient has become feasible. The potential for this approach is most evident in tackling cancer.

If statistics are to be believed, most readers will have had an encounter with cancer, either personally or affecting a close family member or friend. You will know that treatments up until now have tended to be aggressive and non-personalized —a sledge-hammer to crack a nut. Radiotherapy and chemotherapy exact a huge toll on the patient. Whilst such approaches have certainly not been consigned to history, they are starting to be replaced by more specific treatments.

Cancers are fundamentally genetic illnesses, caused by an accumulation of errors over time. Whereas description of a cancer was previously restricted to identifying the tissue in which it was found, for example in the liver or on the skin, and possibly the sort of cells in which it originated, it is now feasible to detect the exact genetic changes that have led to the condition. This opens up the possibility of giving one or more drug that will only kill the mutant cells, not the healthy ones. For example there are now known to be at least ten different subtypes of breast cancer. Some medicines would be ideal to tackle some of these, but useless or even harmful to patients with different forms.

This molecular understanding is also revealing that the underlying cause of cancer in one patient might be the same as the disease found in a different organ for another. When this is the case, it has been demonstrated that a medicine to treat one form of cancer might be applicable to the second. In one example, the drug Vemurafenib, developed to fight skin melanoma, also proved effective against certain types of blood cancer, once it was shown that a crucial genetic change was the same in both cases. This ability to repurpose existing drugs can bring about effective treatment far more quickly than having to start from scratch for the identification and licensing of a new compound.

Ethically, treating someone with a more effective medicine seems like an easy win. Of course, life is not that straightforward. Many of the targeted treatments are spectacularly expensive, and so may be beyond the reach of some patients or health care providers. This brings us back to one of the crucial dilemmas in all of these genomic approaches, disparity of access. Whilst this cannot be grounds for holding everyone back to the lowest common denominator, it is nonetheless a reminder of the need to ensure that the benefits of these technologies are shared as widely as possible, and as quickly as possible.

SUMMARY

The next few years are going to see further growth in the realization of genomic approaches in medicine, and further afield. The potential is revolutionary and exciting, but there are ethical questions that will need to be constantly monitored. These include: the accuracy of results; dealing with unexpected findings; whether anything can be done in the light of any genomic revelation and the cost of doing so; equality of access; and the provision of necessary counselling. There therefore remains plenty for the Grífols Foundation and others to consider during the coming 25 years. ///

ETHICS, HUMAN NATURE AND THE CAUSES OF EVIL

Luciano Floridi

Moral evil is due to the fact that humanity is either good but stupid (let us call this the Socratic anthropology) or intelligent but evil (let us call this the Hobbesian anthropology). From these two philosophical anthropologies derive different ethical and political theories and practices, but above all, different answers to how moral evil can be at least mitigated, if not eliminated.

Humanity has always wondered about good and evil but especially about evil, seen as made up of suffering, fear, disappointment, humiliation, sorrow, offence, abuse, injustice, violence, atrocity, and anything else negative that life has in store for us. Evil plays a leading role in all cultures and civilizations, from the first cuneiform tablets, which speak of unpaid debts, to the Epic of Gilgamesh and the Odyssey. There is no Dante or Shakespeare, Cervantes or Goethe without evil as a great actor in human affairs. Evil is a constant in history. It is also the object of study of ethics, which investigates its nature and causes, why it exists, and how it can be countered.

NATURAL EVIL VS. MORAL EVIL

Philosophers agree on the nature of evil insofar as they distinguish two kinds: the nature-based and the human-made, called moral. An example can clarify the difference. In December 2021, many tornadoes caused deaths and injuries in various states of the United States, especially in the area of Kentucky. Pain, suffering, fear, losses of all kinds ... these were all aspects of *natural evil*, something that even the legal system calls “an act of God”, for which nobody can be held responsible. Still in December, still in the United States, a student killed four people and injured seven others at a Michigan school. Equally devastating effects, but a very different cause, which in this case is entirely and exclusively *moral* because it is made up of human choices and responsibilities. It was an (evil) act of Humanity.

If you rely on similar examples, or consult an ethics textbook, the distinction between natural and moral evil seems clear and uncontroversial. But things quickly get complicated. Natural evil has always been a major headache for many religions, especially Christianity, which sees God as omnipotent, omniscient, and infinitely benevolent. If God can do anything, knows everything, and always wants the good, how do we square that with the sufferings in Kentucky? God’s will? Did people deserve it? Or could God do nothing about it? Whichever way you turn it around, it is a thorny problem that goes by the name, made famous by Leibniz, of theodicy: how to reconcile the existence of God (as described above) with the existence of natural evil.

Leibniz thought that the theodicy problem could be solved by arguing that our world, as a whole, is the best of all possible worlds, despite all its limitations. A little bit like saying that things may not be great, but they cannot get any better than this. Voltaire thought Leibniz’s suggestion was a bad joke, and he famously mocked Leibniz and his philosophy in his classic satire *Candide, or Optimism*. The novella was published in 1759. In it, we find references to historical events, such as the Lisbon earthquake (1755), a natural evil that killed between 12,000 and 50,000 people, one of the worst outcomes in earthquake history; and the Seven

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Years' War (1756–1763), a moral evil that caused between 900,000 and 1,400,000 deaths and is often considered the first global conflict in history. As Voltaire might have said: just imagine if this were not the best of all possible worlds.

The story seems to end here, but in reality, over time, another factor takes over. Could the suffering and losses in Kentucky have been prevented? Tornadoes today are unpredictable. Too sudden and chaotic, they generate too much data, and there is too little time to do the necessary calculations. Nevertheless, we can already do simulations, assign probabilities, play the precautionary card. Most importantly, one day, we may have the data, the models, and the computing power necessary to predict them with sufficient accuracy and reliability. And then there are the buildings. We should build them tornado-proof, as we do with anti-seismic measures in earthquake-prone areas. In other words, as science and technology advance, natural evil does not remain fixed, but is translated more and more into moral evil. That is, if things end badly, it is no longer God's fault, but Humanity's alone. For example, Hegel died of malaria, like Dante. It was a natural evil at the time, but today dying of malaria is an entirely human responsibility. It has morphed into a moral evil. In 2020, there were 241 million cases of malaria worldwide and an estimated 627,000 deaths.[1] Like them, the deaths caused by the Lisbon earthquake today would be a human crime, not something for which to doubt the existence of the God of Christianity. So, Leibniz's idea could be updated in the following version: this is not yet the best of possible worlds, but we are getting there, and in the future, natural evil could be a memory, leaving only human intelligence, freedom, and responsibility to prevent, avoid, minimize, or eradicate evils in the world. In the presence of moral evil, the theological solution is to excuse God and charge humanity with the mistaken use of its freedom. Evil would be an utterly immanent problem, a human problem. Perhaps this is the best of all possible worlds, after all, because it offers humanity the opportunity of removing any natural evil.

PERSISTENCE OF MORAL EVIL

Over time, on the ethical scale, the plate of natural evil is becoming lighter and that of moral evil heavier. Human responsibilities are increasing, not only for the many wrongs we cause —just think of climate change— but also because of the natural evils we can but do not prevent, minimize, or eliminate. Here too, science, technology, and, more generally, human intelligence make a huge difference, for better or for worse. If the student in Michigan had not had a gun, he would not have been able to kill and injure so many people in an instant. Mass shootings (defined as at least four

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[1] https://www.who.int/news-room/fact-sheets/detail/malaria

people shot, plus the shooter) are so common in the United States that there is an entry for each year on Wikipedia. That of 2020 lists 703 people dead and 2,842 injured, for a total of 3,545 total victims. Proof that human stupidity and responsibility are immense because good legislation would be enough to eradicate an evil that is entirely and only moral. Everyone understands this, except some Americans.

This path of translating natural evil into moral evil seems like bad news, but it is not. Because as far as natural evil is concerned – think of the pandemic – there is little to do except transform it into a subsequent human responsibility, for example, in the production and distribution of vaccines to everyone. But as far as moral evil is concerned, one can work to eradicate it, for instance, by getting vaccinated. So, the first step is to transform natural evil into a moral one, from acts of God to human shortcomings. The next is to fight moral evil itself. To do so, one must understand it. Hence the crucial question: why are we evil? Or, as some ethicists would rather put it: why do we behave evilly? Ethics has done much work on this too, but in the end, there seem to be two prevalent interpretations of human nature that explain moral evil. Neither does us credit, but I believe that each usefully captures part of the story, as often is the case.

The first dates to Socrates, but we also find it in the Stoics, Rousseau, or Arendt. We do evil not because we are immoral by nature, but because we do not understand what good is for ourselves and others. Vices, wickedness, and horrors of all kinds are the result of human stupidity, moral ignorance, or some other *epistemic shortfalls*. Then there is another tradition, attributable to Hobbes as its best-known supporter, but which also includes Kant, for example. According to it, moral evil is the fruit of human intelligence at the service of human intrinsic immorality. Each of us pursues our selfish interests and goals as much as possible, and if we stop, it is only because the outcome no longer suits us. The shortfalls are moral, not epistemic. Famously, Kant made this point by saying that “out of the crooked timber of humanity no straight thing was ever made” (this echoes *Ecclesiastes* 1:15 “what is crooked cannot be made straight”, but is more pessimistic than *Luke* 3:5 “[…] and the crooked shall be made straight”.

In summary, and simplifying, moral evil is due to the fact that humanity is either good but stupid – let us call this

THE FIRST STEP IS TO TRANSFORM NATURAL EVIL INTO A MORAL ONE, FROM ACTS OF GOD TO HUMAN SHORTCOMINGS the Socratic anthropology – or intelligent but evil – let us call this the Hobbesian anthropology. From these two philosophical anthropologies derive different ethical and political theories and practices, but above all, different answers to how moral evil can be at least mitigated, if not eliminated.

EDUCATE OR ENCOURAGE

If we are good but stupid, then we must invest in our education: to make people understand more and better what is authentically good for themselves and others, for society and the environment. In this case, the Socratic solution to moral evil is called *Paideia*. Using a trivial example, warning messages on the packaging of cigarettes and other tobacco products concerning their harmful health effects are a typical case of a Socratic approach: more information should lead to better behaviour. These messages have been implemented since 1969. In 2011, a systematic report concluded that “prominent health warnings on the face of packages serve as a prominent source of health information for smokers and non-smokers, can increase health knowledge and perceptions of risk and can promote smoking cessation. The evidence also indicates that comprehensive warnings are effective among youth and may help to prevent smoking initiation. Pictorial health warnings that elicit strong emotional reactions are significantly more effective” (Hammond, 2011).[2] It seems that the Socratic approach may have some merits.

However, if we are intelligent but evil, then one must motivate through incentives and disincentives, which rational and selfish agents will find more or less compelling. Even devils incarnated can be coaxed into doing the right thing if properly nudged. In this case, the solution to moral evil is called *Nomos*, the body of laws and rules that make things work as they should. From a Hobbesian perspective, that is where society must invest in terms of designing its preferred forms of civil cohabitation. Using the previous, trivial example, increasing the price of tobacco is a Hobbesian solution to motivate a rational choice and more virtuous behaviour. According to a recent study, it does have an impact, especially when you do not have much money and you can still give up smoking: “taxation is an effective means of socially-enacted preventative medicine in deterring youth smoking” (Ding, 2003).[3]

The history of civilizations oscillates between *Paideia* and *Nomos*, preferring one or the other depending on the contexts. But these are not two incompatible visions. Except for a few cases of pure holiness and utter wickedness, we are almost all a little bit good but stupid and a little bit

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[2] Hammond, D. (2011). *Health warning messages on tobacco products: a review*. Tobacco Control. 20 (5):327-337.

[3] Ding, A. (2003). *Youth are more sensitive to price changes in cigarettes than adults*. The Yale journal of biology and medicine. 76 (3):115.

evil but intelligent. For this reason, innovation and development must support both *Paideia* and *Nomos* to make us Socratically intelligent and Hobbesianly good. The tricky bit is to reach an equilibrium that is also *tolerant* of individual preferences and choices (Floridi, 2015, 2016).[4,5] Which is a somewhat philosophical way of saying that society can hope to improve only if it invests in science and technology, to eliminate natural evil or translate it into a moral one, and in education and rules, to reduce moral evil, and perhaps even eliminate it one day, to make any negative impact of an act of God a thing of the past. ///

Acknowledgements
I am very grateful to Emmie Hine and Mariarosaria Taddeo for their feedback on previous versions of this article.

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[4] Floridi, L. (2015). *Toleration and the Design of Norms. Science and Engineering Ethics*. 21 (5):1095-1123. doi: 10.1007/s11948-014-9589-x.

[5] Floridi, L. (2016). *Tolerant Paternalism: Proethical Design as a Resolution of the Dilemma of Toleration*. Science and Engineering Ethics. 22 (6):1669-1688. doi: 10.1007/s11948-015-9733-2.

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★
Lidia Casanueva, Pedro Ruiz, Juan Ignacio Sánchez, and José Carlos Mingote
Impacto de un programa de mejora en la atención a los niños y sus famílias en el proceso de morir en una Unidad de Cuidados Intensivos Pediátricos

★
Jordi Vallverdú
e-Biotecnología: simbiosis de valores

📖
Víctor Clariana and Xavi Durán
Gen Ètica

🏆
Pablo de Lora
Justicia para los animales: la ética más allá de la humanidad

2004-2005

★
Juan Antonio Barcia
Tratamiento integral del paciente con tumor cerebral: comunicación y toma de decisiones como elementos clave en la promoción del bienestar

★
Antonio Casado
Aproximación filosófica a la enfermedad de Huntington: diseño de un marco ético para investigaciones en genética molecular

★
Armando Ortiz
Acompañamiento del paciente: ¿una experiencia de aprendizaje sobre el significado de la enfermedad?

★
Jordi Vallverdú
Las fronteras del lenguaje bioético: un nuevo pensar

📖
Albert J. Jovell
Deseo de morir, voluntad de vivir

🏆
Salvador Tarodo
Libertad de conciencia y derechos del usuario de los servicios sanitarios

2005-2006

★
Marcel Cano
El papel de las biotecnologías en la construcción de consenso social

★
Montse Esquerda
Escala de competència del menor de Lleida

★
María Jesús Gómez and María del Carmen Sánchez
Escala pronóstica de la negación del ingreso en UCI como forma de LET (EPNIL)

★
Glòria Miró
Factores asociados al conocimiento y realización de documentos de voluntades anticipadas en enfermos con patología neurodegenerativa

📖
Milagros Pérez
Morir en España. El reto de una muerte digna. Atrapados en la tecnología.
La muerte clandestina

🏆
Daniel Soutullo
Biología, cultura y ética: crítica de la sociobiología

2006-2007

★
Asunción Esteve
Patentes sobre los resultados de la investigación con células madre

★
Ernest Güell and Antonio Pascual
Descripció de les característiques dels pacients ingressats a una unitat de cures pal·liatives que verbalitzen desitjos de mort o demanda d'eutanàsia

★
Miguel Moreno
Convergencia de tecnologías con fines de mejora humana: aspectos éticos y sociales

★
Juan Carlos Siurana
Problemas éticos en la comunicación con los pacientes inmigrantes infecciosos de larga duración y con tratamientos paliativos en el Hospital Doctor Moliner de Portacoeli, Valencia

📖
Isabel Perancho
Las relaciones con la industria, por fin en el código deontológico, Investigación independiente: ¿está en vías de extinción?, Octavi Quintana, director de investigación en salud de la Comisión Europea: No sirve de nada guardar cordón en un centro privado, ¿Son fiables las revistas médicas?, España lidera la búsqueda de nuevas fuentes de órganos útiles para el implante

🏆
Íñigo de Miguel
La clonación, diez años después

2007–2008

★
Araceli Teixidó
Demència i principi d'autonomia. Anàlisi qualitativa del procés d'informació diagnòstica en pacients amb demència a la Corporació de Salut del Maresme i la Selva: s'ha d'incloure el malalt dement en el procés d'informació de la seva malaltia?

★
Pablo Hernando
Validación de la escala MacCAT-T: herramienta para evaluar la capacidad en la toma de decisiones sanitarias

★
María Luisa Martínez
Donació de mostres de teixit per investigació: percepcions i disponibilitat entre malalts oncològics

★
Asaf Grauer
Problemes jurídics dels biobancs

🏆
Antonio Casado
Introducción a la ética asistencial: bioética para legos

📖
30 minuts, Televisió Catalunya
Un nadó per salvar els fills

2008–2009

★
José Luís Pérez
La eugenesia positiva y su impacto en la práctica deportiva

★
Ana Lucía Noreña and Elena Ferrer
Protocolo de investigación: Escuchando las voces de los niños. Aspectos éticos del proceso de informar a un menor hospitalizado

★
Maria Isabel Tamayo
Portal sobre voluntades anticipadas en el mundo

★
Josefa Fernández
El trabajo social con familias: la responsabilidad de los trabajadores sociales en la autodeterminación de los colectivos más vulnerables

🏆
David Rodríguez-Arias
Muerte cerebral y trasplante de órganos

📖
Einstein a la platja, Barcelona Televisió
Adéu als gens omnipotents

2009–2010

★
Sara Guila Fidel
Protección de la confidencialidad en las historias clínicas informatizadas: los pacientes en la consulta de Salud Mental hospitalaria

★
Montserrat Guillaumet
L'experiència de ser cuidat en un hospital. Perspectiva des del client immigrat econòmic extracomunitari

★
José Luís Villanueva
Ventilación mecánica, gastrostomía percutánea y toma de decisiones en pacientes con ELA: encuesta sobre la opinión de los pacientes, familiares y médicos

★
Joan Canimas
Guia orientativa per a guardadors de fet de persones amb malaltia d'Alzheimer als quals es proposa participar en projectes de recerca clínica

🏆
Josefina Goberna
Dones i procreació: ètica de les pràctiques sanitàries i la relació assistencial en embaràs i naixement

📖
30 minuts, Televisió de Catalunya
Decidir la mort

2010–2011

★
Roser Marquet
La percepció de confidencialitat en les persones grans de l'àmbit rural

★
Marta Roca
La subrogació uterina enfront del sistema de filiació. Anàlisi d'un fenomen actual

★
Magí Farré and Astrid Hernández
Información de placebo en los ensayos clínicos y su influencia en la decisión de los participantes

★
Anna Rodríguez and Joaquín T. Limonero
Reaccions emocionals i accions dels nens i adolescents davant de la malaltia oncològica avançada dels pares

🏆
Eduardo Alfonso Rueda
Incertidumbre, autonomía y uso de pruebas genéticas predictivas: Más allá del consentimiento individual

📖
Raquel Cors. Gran Angular
Zeladors

2011–2012

★
Michelle Piperberg
Sobre la "persona". Aproximación a las discusiones en torno al final de la vida

★
Rosa María Medina and Sandra Fernández
La tríada equipos médicos-familiares-pacientes en estados de intersexualidad. El caso español

★
Germán Diestre
Implementación de la Planificación Anticipada de Decisiones en el Centre Sociosanitari Albada: Estudio Cualitativo

★
Iván Ortega and David Rodríguez
Organ Donation in Spanish Emergency Ambulance Services (ODISEAS)

🏆
Ester Farnós
Consentimiento a la reproducción asistida. Crisis de pareja y disposición de embriones

📖
Mònica López
La veritat ajuda a morir

2012–2013

🏆
Anna Falcó
Análisis de la Conflictividad Ética en los profesionales de Enfermería de las Unidades de Cuidados Intensivos

★
Elvira Pértega
El uso de contenciones físicas en unidades pediátricas de psiquiatría: ¿una práctica clínica ética?

★
Noelia Igareda
El derecho a conocer los orígenes biológicos versus el anonimato en la donación de gametos

★
Silvia del Castillo
Manejo actual en España de los desfibriladores implantables en enfermos terminales y en el cuidado al final de la vida. ¿Se plantea la posibilidad de desactivación?

★
María Amparo Bodi
Descripción de las prácticas de limitación de la terapia de soporte vital en una UCI e impacto en la potencialidad de donación tras asistolia controlada

📖
Marta Espar
Recull de 20 reportatges sobre recerca biomèdica publicats a XploreHealth

🎓 1
Yousra El Kasmi
La polèmica sobre el rebuig a la transfusió de sang

🎓 2
Ojanta Mahmud Jordà
L'ètica aplicada en les cures pal·liatives i el tractament de malalts terminals

🎓 3
Gemma Cardona y Mercè Gil
Bioètica: eutanàsia

2013–2014

★
Omar García
El concepto de autonomía del DSM 5: rasgos y posibles implicaciones de su modificación

★
Sergio Ramos
El documento de voluntades anticipadas en salud mental

★
Oriol Yuguero
Estudio de la empatía de los médicos y enfermeras de Atención Primaria de la Región Sanitaria de Lleida y su relación con las variables clínicas

★
Míriam de la Flor
Programa de toma de decisiones compartida en el cáncer de mama con mastectomía. El derecho de la mujer a decidir

★
Jordi Cabós
Epidemiologia de la resiliència

★
Priscila Giraldo
Comunicación y disculpa después de un error médico

🎓 1
Beatriz de Peray
Les implicacions ètiques en el diagnòstic genètic preimplantacional

🎓 2
Noemí Aranda
Un giro de 180º

🎓 3
Eloi Güell
El futur de la naturalesa humana

⚗ 1
Escola Garbí Pere Vergés d'Esplugues de Llobregat
Biotecnologia i societat

⚗ 2
Escola Solc Nou de Barcelona
Cuidem als nostres avis. Projecte d'humanització de la salut

⚗ 3
Institut El Cairat d'Esparreguera
Gust i passió per investigar

2014–2015

★
Gemma Robleda and Josep-E. Baños
L'avaluació del dolor en persones adultes sense capacitat de comunicació. Un anàlisi bioètic en les unitats d'hospitalització de pacients crítics

★
Elena Lauroba
La protecció jurídica de les persones intersexuals: repensar des del dret les assignacions (arbitràries?) de gènere

★
Sonia Jimeno
Les patents biotecnològiques: als límits de la legalitat

★
Loreto María García
Constructe d'un instrument per quantificar el compromís professional en infermeria

★
Lydia Feito and Tomás Domingo
Bioètica narrativa: aplicació del model als àmbits clínic i educatiu

★
Maite Cruz
La no vacunació com a punt de trobada: analitzant discursos per construir ponts

🎓 1
Marta Galisteo
Eugenèsia Actual ¿Cal intervenir per millorar la genètica humana?

🎓 2
Mariona Asensio and Júlia Marquès
La intersexualitat, el trencament d'un sistema binari

🎓 3
Mireia Jaimot
Umbilical Cord Blood Stem Cells: business or science

⚗ 1
IES Fontanelles de Les Borges del Camp
Joc de Rol de l'Hospital

⚗ 2
Institut Juan Manuel Zafra
Fer ciència per comunicar ciència

⚗ 3
Escola Sant Gervasi Cooperativa de Mollet del Vallès
La donació de sang i de teixits, ètica científica i realitat social

2015–2016

★
Francisco José Eiroa
L'estat de les preferències dels pacients en l'àmbit de la pràctica de la salut mental a Catalunya

★
Alejandra Fernández
Ética del cuidado aplicada en la unidad de cuidados intensivos

★
Miquel Domènech
Ètica per a robots: Algunes consideracions per al disseny de robots socials per a hospitals infantils

★
Núria Oriol
Document Informatiu de Compromís (DIC) en les adaptacions dietètiques en la disfàgia

★
Janet Delgado
Enfoques relacionales: vulnerabilidad y autonomía en bioética

★
Rosana Triviño
Estudio comparativo de los protocolos de acceso a la interrupción de la gestación en la Unión Europea (ProtoAccess)

🎓 1
Berta Mateos
El debat ètic al voltant de la neuromillora

🎓 2
Elena Cortina
El Pol i l’arbre dels records. La bioètica i la mort

🎓 3
Pere Valls
Crawl and Roll

⚗ 1
IES Elisa y Luis Villamil de Vegadeo
IES Galileo Galilei de Navia
IES Marqués de Casariego de Tapia de Casariego
Bioètica a les aules

⚗ 2
IES Rosalía de Castro de Santiago de Compostel·la
Implicacions ètiques de la intel·ligència artificial

⚗ 3
Escola Antoni Gaudí de Sant Boi de Llobregat
Terra i humans, units de les mans

❦⚗❦
La Salle de Bilbao por el proyecto
Consciència, drogues i fàrmacs: entenc, aprenc, actuo

❦⚗❦
Escola Garbí Pere Vergés d’Esplugues de Llobregat
Com introduir la bioètica a l’escola?

❦⚗❦
IES Isidra de Guzmán d’Alcalá d’Henares
Actua! és la teva responsabilitat

2016–2017

★
Júlia Martín
Projecte Horitzons. Proposta metodològica de gamificació de la pedagogia hospitalària basada en la bioètica narrativa i en el model d’humanització de l’assistència als menors hospitalitzats

★
Beatriz Campillo
Construcción y determinación de propiedades psicométricas de un cuestionario para evaluar la percepción del respeto y mantenimiento de la dignidad en pacientes hospitalizados (CuPDPH)

★
Hugo Viciana
Modos de desacuerdo en bioética: el público y los expertos

★
Sabel Gabaldón
La transexualidad en niños y adolescentes. Aspectos éticos de su categorización y tratamiento

★
Ion Arrieta
Psoriasis y autonomía ejecutiva: una propuesta de mejora de adherencia de los pacientes al tratamiento de la psoriasis

★
Christian Villavicencio
Planificación de Decisiones Anticipadas (PDA) y la comunicación en pacientes con enfermedad crónica compleja y con enfermedad crónica avanzada

🎓 1
Joana Krausse
Dilemes ètics d’una llarga vida

🎓 2
Sara Clota
Bioètica i residències per a la Gent Gran

🎓 3
Wiam Koubiss
Nascuts per necessitat: Bioètica del nadó medicament

⚗ 1
Institut de Sentmenat
El pensament natural: bondat i esforç

⚗ 2
Col·legi Mare de Déu dels Àngels de Barcelona
Robètica

⚗ 3
IES Xunqueira II de Pontevedra
Misión a Marte

❦ ⚗ ❦
Escola Sant Gregori de Barcelona
La solidaritat intergeneracional i la cura del medi ambient

🎥
Irene Domènech, Haydée Vila y Jenny Berengueras
Només era un gos

2017–2018

★
Ana María González
Uso ético de las redes sociales en el caso de los trastornos de conducta alimentaria

★
Albert Granero
Puesta en marcha de un proceso de Planificación de Decisiones Anticipadas en pacientes con Trastorno Mental Severo en un Centro de Salud Mental

★
Andreu Segura
L'ètica de la ignorància i l'ètica de incertesa. Elements per a comprendre i prevenir la iatrogènia

★
Mònica Sumoy
Reflexiones éticas sobre la representación del cuidado del ser humano en el cine

★
Priscila Giraldo
La reconciliación después del error médico: la mediación como herramienta de ayuda a las víctimas

★
Silvia Poveda
Barreras en la gestión del Documento de Voluntades Anticipadas y Planificación de Decisiones Anticipadas en servicios de Urgencias y Emergencias Médicas

🎓 1
Marta Vecino
Ciència i bioètica en la ficció

🎓 2
Laia Pérez
El consentiment informat en assajos clínics amb pacients pediàtrics

🎓 3
Maria Bretones
El Diagnòstic Genètic Preimplantacional

⚗ 1
Col·legi Sant Gabriel de Viladecans
La Real Expedición Filantrópica de la Vacuna

⚗ 2
Escola Betània Patmos
Canviem?

⚗ 3
Escola Les Pinediques de Taradell
L'Arbre dels Drets de l'Infant

❦ ⚗ ❦
Centro San Juan de Dios de Valladolid
Capaces con alma

❦ ⚗ ❦
Institut Quatre Cantons del Poblenou
Humanitzar la tecnologia

❦ ⚗ ❦
Institut Berenguer d'Entença de Vandellòs i l'Hospitalet de l'infant
El conta contes ambiental

🎥
Núria Jar
Morir abans de néixer

2018–2019

★
Gonzalo Díaz and Alberto Molina
Pluralismo y muerte: Desafíos éticos y actitudes de los profesionales en relación a la diversidad de criterios en la determinación de la muerte

★
Maria F. Jiménez
Sensibilidad moral de estudiantes de enfermería de grado y posgrado

★
César Palacios
La ética de las técnicas de remplazo mitocondrial para tratar la Infertilidad

★
Alberto Sandiumenge
Evaluación de la influencia de la implementación de programas de donación en asistolia controlada en los cuidados a final de la vida

★
Jordi Mundó
Pacients agents. Repensar l'autonomia del pacient des d'una perspectiva fiduciària

★
María del Carmen Gete-Alonso and Judith Solé
Las nuevas maternidades y paternidades, las "nuevas formas" de tener hijos y sus implicaciones éticas

🎓 1
Anna Carbó
Medicina digna, mort digna

🎓 2
Diana Gallardo and Mar Trinidad
El llegat del Dr. Frankenstein

🎓 3
Paula Cama
Institut de Celrà por "El maltractament animal"

⚗ 1
Institut Rafael Casanova
Planeta B

⚗ 2
Salesianos Pamplona
Electrónica y TEA

⚗ 3
Escola Pia de Granollers
Bioètica

⚗
Institut Antoni Pous i Argila
1,2,3 Acció

⚗
Institut Sunsi Móra
Som CEA

🎥
Marta Espar y Maiol Virgili
Bailar la locura

2019–2020

★
Anna Falcó and Loris Bonetti
Influencia de la crisis sanitaria por COVID-19 en la conflictividad ética de profesionales de cuidados intensivos de Cataluña y Lombardía. (Quali – ETIC – COVID-19 Research)

★
Rebeca Pardo
Ética de las imágenes de la enfermedad, la muerte y el duelo en tiempos del COVID-19

★
Josefina Goberna
Dar a luz en tiempos de pandemia COVID-19: Implicaciones éticas de la atención sanitaria a la maternidad

★
Andrea Rodríguez-Prat
La muerte en soledad desde la perspectiva de supervivientes COVID-19. Un estudio fenomenológico

★
Joaquín Hortal, Maite Cruz and Javier Padilla
Una de cal y otra de arena: reticencia de la ciudadanía a la vacunación de la COVID-19 y rechazo de la vacuna de la gripe entre los profesionales sanitarios

★
Jordi Muñoz
Salut, democràcia i llibertat. Els dilemes ètico-polítics de la pandèmia

🎓1
Carlos Barata
Edición genética

🎓2
Noa Calvo
La mutilació genital femenina

🎓3
Bet Corominas
Les malalties de la pobresa. Més enllà d'un problema sanitari

⚗1
Institut Ribot i Serra de Sabadell
Diari d'un confinament

⚗2
Escola EDUMAR de Castelldefels
La Importància de les Vacunes

⚗3r
CEIP Reyes Católicos de Granada
CON-CIENCIANDO: un laboratorio al aire libre

❦⚗❦
Escola Virolai de Barcelona
Què ens fa humans?

🎥
Patrícia Franquesa
Ole mi coño

❦🎥❦
Clara Camprubí
Segundina Flores

2020-2021

★
María del Mar Cabezas
Autonomía y vulnerabilidad infantil: Retos bioéticos para la salud psicosocial de la infància desde el Enfoque de las Capacidades

★
Montserrat Puig
Impacte de la pandèmia COVID-19 en el sistema emocional la salut i la qualitat de vida de les persones usuaries de les residencies per a persones amb discapacitat

★
Rosauro Varo
Racismo, medicina colonial y salud global: un estudio cualitativo de opinión sobre ética de las decisiones en investigación sanitaria en África

★
Jon Rueda
Gen-Ética Experimental: Las bases cognitivas de las actitudes morales sobre las tecnologías genéticas y genómicas emergentes

★
Núria Vallès and Júlia Pareto
Controvèrsies ètico-polítiques en la introducció de sistemes d'intel·ligència artificial en salut pública. Un estudi de cas sobre l'estratègia de vacunació contra la COVID-19 a Catalunya

★
Pau Miquel Diego
Les narratives clíniques de la mort: una oportunitat per al desenvolupament ètic dels professionals?

🎓1
Bruna Coll
Les "cookies" de la genètica

🎓2
Ingrid Jané
Els ventres de lloguer. La mercantilització del cos de la dona

🎓 3
Aitana Cantó
La conflictivitat ètica en els sanitaris d'UCI durant la pandèmia de la COVID-19

🎥
Laura Corominas, Laura Serra, Clara Serrano, Gerard Simó, Ariadna Ulldemolins and Pau Vall
La nit no fa vigília

🏅🎥
Miguel López
Ponto final

⚗ 1
Institut Baix Montseny de Sant Celoni
APS Projecte comunitari sobre la resistència antimicrobiana

⚗ 2
CRA la Espiga de Zurbarán
Cooperativa Junior Salud Torvis

⚗ 3
Escola Diocesana de Navàs
BOSC

2021–2022

★
Juan Francisco Roldán
Adaptación y validación del cuestionario "Impatient Dignity Scale (IPDS)". Estudio multicéntrico

★
Núria Masnou
Anàlisi de la relació del personal sanitari amb la mort a partir de l'aplicació de la LORE (Llei orgànica 3/2021, de 24 de març, de regulació de l'eutanàsia)

★
Maria Esperança Ginebra, Elena Laouroba and Joan Escarrabill
Consentimiento informado y toma de decisiones compartidas: construcciones jurídicas y experiencias médicas para salvaguardar la autonomía de los pacientes

★
Mar Vallès, Iris Parra and Ramón Ortega
Narrativas de final de vida de pacientes que solicitan la ayuda para morir

★
Adrián Villalba and Miguel Moreno
Gametos artificiales o cómo nos reproduciremos mañana: Un marco normativo para determinar la moralidad

★
Jaime Fons
Portal del donante: herramienta digital para mejorar el proceso de consentimiento informado en la donación de muestras biológicas con fines de investigación

🎓 1
Lúa Abad
CRISPR las tijeras moleculares con las que podrás cortar el ADN

🎓 2
Andrea García
Artificial Intelligence: the (r)evolutionary way to transform medicine

🎓 3
Ovidi Mallafré
Bioètica i mort digna

⚗ 1
Escola Pia Sitges
Amb la vida a les butxaques

⚗ 2
Escola Mossèn Joan Batlle
Plàstic 0

⚗ 3
INS Bellvitge
Comunicació: Ètica, Ciència i Tecnologia

🏅⚗
Escola Aldana
L'amistat no té edat

🎥
Carla Sospedra
La dona invisible

🏅🎥
Montse Pujol
Les culpables

PICTURES TO REMEMBER

Celebrating 25 years of existence leads us to look back and evoke the most important moments of this period. With this photographic selection, we recall in images the evolution of the Foundation from 1998 to the present day.

1998

Presentation of the Víctor Grífols i Lucas Foundation at La Pedrera.

1999

Bioethics Awards and Grants Ceremony.

1999

Àngel Puyol was the first awarded with the Bioethics Research Award. Víctor Grífols i Lucas presented the award.

2000

Federico Mayor Zaragoza was the guest speaker at the Awards and Scholarships ceremony.

2000

Bioethics Forum on The Biological Frontiers of Reproduction, with Victòria Camps, Joaquim Calaf, Diana Guerra, Santiago Ramentol, Encarna Roca and Lluís Monset.

2001

Vladimir de Semir, Victòria Camps and Gema Revuelta at the seminar on *Ethics in medical communication*.

2002

Board of Trustees of the Foundation. Santiago Aragonés, Victòria Camps, Neal Ball, Manel Canivell, Jordi Camí, Ramón Bayés (above), Encarna Roca, Francesc Abel, Josep Egozcue and Montserrat Busquets (below).

2003

Rational use of medicines seminar.

2004

Manel Canivell, Josep Egozcue, Marc Antoni Broggi, Xavier Carné. Ramón Bayés, Victòria Camps, Montserrat Busquets, Guillem López, Neal Ball and Encarna Roca.

2005

Josep Egozcue at a meeting of the Board of Trustees.

2006

Presentation of the document *Las prestaciones privadas en las organizaciones sanitarias públicas*, with Guillem López, Miquel Vilardell, Victòria Camps and Àngel Puyol.

2007

Josep Vila, Merè Pérez Salanova and Moisès Broggi at the *Autonomy and Dependency in Old Age* conference.

2008

10th Anniversary of the Foundation and inauguration of the Grífols Museum, with Víctor Grífols Roura, JoanClos, Victòria Camps and Víctor Grífols i Lucas.

2008

The Ethical Questions sessions begin, small-format debates on topical issues. The first was devoted to sex education.

2008

Seminar *Ethics in care services for people with disabilities*.

2009

Seminar *Ethical challenges of e-health*.

2009

Eric Cassell, guest speaker at the II Egozcue Conferences.

2010

Awards and Scholarships Ceremony, with Mark Siegler as guest speaker.

2011

Seminar on health management organised with the Centre for Research in Economics and Health from the Pompeu Fabra University.

2012

Thomas Murray at the lectures on *Ethics and synthetic biology*.

2013

Thomas Pogge at the *Scope and limits of solidarity in times of crisis*, organised with the Probitas Foundation.

2013

Yousra El Kasmi won the First Prize for Research Work in Bioethics in the first edition of this award.

2013

Carol Gilligan was the guest speaker at the conferences on the *Ethics of care*.

2013

The lectures given by Carol Gilligan were one of the Foundation's most successful activities.

2014

Francisco J. Ayala gave a lecture on the roots of morality at the Awards and Scholarships ceremony.

2014

Peter Singer gave two lectures on ethics and altruism at the Centre de Cultura Contemporània de Barcelona.

2015

Tribute to Víctor Grífols i Lucas.

2015

Creation of the Grífols Foundation Chair of Bioethics.

2015

Seminar organised with the Nuffield Council of Bioethics on ethics and research with children.

2016

Crisis and mental health in children and young people, organised with the Probitas Foundation.

2016

James L. Bernat at the conferences *Do we need to rethink the concept of death?*

2016

Salvador Macip at the session Bioethics for young people at the Barcelona International Youth Science Challenge campus.

2016

Jean-Pierre Changeux and Victòria Camps at one of the conferences organised at the CCCB during the exhibition *+Humans.*

2017

Joseph J. Fins at the seminar *Ethics Committees and Clinical Consultants*.

2018

Joan Pons, Pere Ibern, Bonaventura Clotet, Manel Esteller, Mercè Boada, Núria Terribas, Ezekiel Emanuel and Victòria Camps at the conferences *New scenarios in health and clinical research*.

2018

Ezekiel Emanuel at the conferences *New scenarios in health and clinical research*.

2018

The students of L'Escola Les Pinediques of Taradell present their project *The Tree of the Childs*, which earned them the third Ethics and Science Award.

2019

Antonio Centeno, Joan Canimas and Pilar Ariño at the seminar *Supporting the sexuality of people with functional diversity*.

2019

Welcome speech by Josep Eladi and Núria Terribas at the 1st International Congress of Bioethics, which focused on the topic of *Pedagogy in bioethics education*.

2021

Fundació is awarded on the National Research Prizes organized by the Generalitat de Catalunya. The Foundation received the Scientific Patronage Award.

2021

Presentation ceremony of the National Research Prizes awarded by the Generalitat de Catalunya.

2021

Presentation of the Ethics and Science Awards as part of an online ceremony with all the finalists. After the pandemic, the Foundation's activities were adapted to the virtual format.

2022

Recipients of the Bioethics Prizes and Grants.

2022

Group photo of the attendees and participants of the 2nd International Congress of Bioethics under the title *Horizons in Bioethics*, held at the University of Vic on 17-18 November.

2023

Rosa Maria Pujol introducing Rosauro Varo's lecture *Racism, colonial medicine and global health*, organized by Friends of Unesco of Barcelona.