



International Chair in Bioethics 14th World Conference  
WMA Cooperating Centre

# Bioethics, Medical Ethics and Health Law

March 7-10, 2022  
Porto Palacio Hotel  
Porto, Portugal

*Program and Book  
of Abstracts*

Bioethics, Medical Ethics and Health Law | March 7-10, 2022 | Porto, Portugal

ISBN 978-965-599-104-8



978-965-599-104-8

The design of the cover of the book: Mrs. Gili Carmi

PROGRAM AT A GLANCE  
(subject to onsite changes)

Monday, 7 March, 2022							
10:30 - 11:00	Coffee Break						
11:00 - 12:30	Opening Session (This session will also be transmitted live)						Porto Hall
12:30 - 13:30	Lunch Break						
	HALL A Douro South	HALL B Douro North	HALL C Minho	HALL D Lima	HALL E Cavado	HALL F Tâmega	HALL G Corgo
13:30 - 15:00	Ethical Aspects of E-Medicine	Human Rights I (Spanish)	Holocaust I	Alcohol & Drugs I	Bioethics: History & Future I	Autonomy I	Ethics Committees I
15:00 - 16:00	Neuro-Ethics	Meaningful Youth Engagement in Ethics & HR	Autonomy II	Informed Consent I	Justice	Bioethics General I	Bioethics Education I
16:30 - 17:00	Coffee Break						
17:00 - 18:00	Medical Ethics: Digital Era I	Reproduction I	Ethics Committees II	Bioethics General II	Pregnancy Termination	Death & Dying End of Life I	Medical Ethics & Law I
Tuesday, 8 March, 2022							
08:30 - 10:30	Cultural Pluralism I	Israeli Medical Association	Holocaust II	Bioethics General III	Informed Consent II	End of Life I	Death & Dying I
10:00 - 10:30	Coffee Break and Poster Viewing						
10:30 - 12:00	Nursing, Law & Ethics	Bioethical Dilemmas in the Beginning of Life	Holocaust III	Bioethics Education II	Bioethics General IV	Medical Ethics I	Human Life: Sacred Life
12:00 - 12:30	Medical Law I	Medical Ethics: Digital Era II	Ethics Education: Tools & Methods I	Genetics: Ethical Aspects I	Discrimination	Human Dignity	Bioethics General V
13:30 - 14:30	Lunch Break						
14:30 - 16:00	World Medical Association Session: International Code of Medical Ethics (This session will also be transmitted live)						
16:00 - 16:30	Coffee Break and Poster Viewing						
16:30 - 17:30	Medical Research I	CPME AI in Healthcare I	Children & Youth	Medical Ethics: Digital Era III	Bioethics General VI	Ethics Education: Tools & Methods II	Organ Transplantation I
Wednesday, 9 March, 2022							
08:30 - 10:00	Genetics: Ethical Aspects II	Organ Transplantation II	Medical Ethics II	Assisted Suicide	Patient's Rights	Law & Ethics I	Bioethics General VII
10:00 - 10:30	Coffee Break and Poster Viewing						
10:30 - 12:00	Healthcare Services & Ethics I	Defensive Medicine CPME II	Bioethics General VIII	Benefit & Harm I	Medical Ethics III	Environment Ethics	Veterinary, Medical & Animal Research Ethics
12:00 - 12:30	Genetics: Ethical Aspects III	Medical Errors & Human Dignity	Medical Ethics IV	Bioethics General IX	Confidentiality & Informed Consent	Benefit & Harm II	Human Rights II
13:30 - 14:30	Lunch Break						
14:30 - 16:00	Healthcare Services & Ethics II	Health & Gender Equality	Death & Dying II	Bioethics Education III	Bioethics General X	Medical Ethics V	Genetics: Ethical Aspects IV
16:00 - 16:30	Coffee Break and Poster Viewing						
16:30 - 17:30	Bioethics Education IV	Law & Ethics II	Holocaust IV	Cultural Pluralism II	Human Rights III	Doctor's Rights	Bioethics General XI
Thursday, 10 March, 2022							
08:30 - 10:00	Reproduction II	Bioethics Education V	Death & Dying End of Life II	Alcohol & Drugs II	Medical Ethics & Law	Bioethics: Gender	
10:00 - 10:30	Coffee Break and Poster Viewing						
10:30 - 12:00	Reproduction & Surrogacy	Medical Law II	Bioethical Discussions: Covid-19 Pandemic	Benefit & Harm III	End of Life II	Bioethics: History & Future II	Clinical Trials
12:00 - 13:00	Closing Session						Porto Hall



UNESCO Chair in Bioethics  
The books are free under

[www.unesco.org/ethics](http://www.unesco.org/ethics)



## International Chair in Bioethics 14th World Conference on

# Bioethics, Medical Ethics and Health Law

Porto Palacio, Porto, Portugal | 7-10 March, 2022

Under the auspices of:



Faculty of Medicine of the University of Porto



Portuguese Association of Bioethics

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## MESSAGE FROM THE CONFERENCE CO-PRESIDENTS

We wish to welcome each and every participant and extend our gratitude for the support of the 14th World Conference and for joining us in Porto, Portugal.

This conference has been postponed a few times due to matters outside of our reach and we sincerely thank those who despite it all saved their registrations to be here with us in person.

The World Conference offers its participants an international platform for fruitful scientific discourse on more than 60 topics and subtopics in the fields of bioethics, medical ethics and health law.

We are pleased to inform you that the number of centers ("Units") of the Chair has recently grown and now consists of 248 centers located in universities on five continents.

The Chair currently operates about 3,000 volunteers on the Steering Committees of its units - The International Forum of Teachers Chair (IFT) has more than 1,200 educators in more than fifty countries

- operates many departments which you can see on page 6
- publishes educational materials for teachers and students, and holds local, national and international seminars and conferences
- enjoys fruitful cooperation with the World Medical Association (WMA) and the International Federation of Medical Students Associations (IFMSA).

Personal Invitation:

You are welcome to send an email to the Chair in order to receive information about any of the following programs to the following address: [international.bioethics.chair@gmail.com](mailto:international.bioethics.chair@gmail.com)

- Establish a New Unit at your University
- Join the Teachers Forum of the Chair
- Join the Project of Bioethics for Youth and Children
- Join the Project of Bioethics in the Holocaust
- Register for the Doctoral Program (PhD) on Bioethics

We wish you an interesting, fruitful and pleasant stay at the Conference.

Keep Healthy and Go Safely!!



**Prof. Amnon Carmi**  
Co-President of the Conference



**Prof. Rui Nunes**  
Co-President of the Conference

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## CONFERENCE CO-PRESIDENTS AND COMMITTEES

### Co-Presidents of the World Conference

Prof. Amnon Carmi and Prof. Rui Nunes

### International Honorary Committee

Prof. Leonid Eidelman

Prof. David Gordon

Prof. Miguel Jorge

Prof. Frank Ulrich Montgomery

Dr. Rajan Sharma

### International Organizing Committee

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Prof. Moty Benyakar

SN Rita Cavaco

Prof. Russell D'Souza

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Dr. Otmar Kloiber

Prof. Sashka Popova

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Ms. Annabel Seebohm

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Adv. Leah Wafner

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Prof. Daniel Fu Cheng Tsai

Dr. Tami Karni

Prof. Rui Nunes

Prof. Vojin Rakic

Prof. Yehuda Ullmann

Dr. Miroslava Vasinova

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Dr. António Rui Leal

Prof. Paulo Maia

Prof. Luísa Neto

Dr. Sofia B. Nunes

Dr. Evelyn Oliveira

Prof. Helena Pereira de Melo

Prof. João Proença Xavier

Prof. Francisca Rego

Prof. Miguel Ricou

Prof. Anna Olsson

Prof. Natália Oliva Teles

## GOVERNING COUNCIL

The Governing Council of the Chair was established on 1 September 2021. It consists of the following Heads of the Chair's Departments and Divisions:

Prof. Amnon Carmi, Head

Prof. Yoram Blachar	Head of WMA Department
Prof. Rui Nunes	Head of the Portuguese Language Countries Division, Head of PhD on Bioethics Division, Head of Palliative Care Department, Co- Head of Ibero American Division
Prof. Shai Linn	Head of Scientific Literature Review Department
Prof. Russell D'Souza	Head of Asia-Pacific Division, Head of the Education Department, Editor-in-Chief of the Chair's Journal
Dr. Miroslava Vasinova	Head of Bioethics for Youth & Children Department, Coordinator of the Chair's Newsletter
Prof. Vojin Rakic	Head of European Division
Prof. Sashka Popova	Head of the International Forum of Teachers (IFT)
Prof. Moty Benyakar	Co- Head of the Ibero- American Division
Prof. Daniel Fu Chang Tsai	Head of Website Department
Prof. Effa Pierre	Head of African Division
Prof. Daniela Keidar	Head of Behavioral Bioethics Department
Adv. Ilan Keidar	Head of Law Department
Mrs. Shoshana Golinsky	Administrative Manager of the International Network of Units
Dr. Tessa Chelouche	Co-Head of Bioethics and the Holocaust Department
Dr. Stacy Galin	Co-Head of Bioethics and the Holocaust Department
Prof. Praveen Arora	Head of World Bioethics Day Department (WBD)
Dr. Tormo Dominguez Maria	Head of Monthly Case Department
Prof. Wu Chong	Head of Chinese Division
Prof. Mary Mathew	Head of Bioethics and Art Department
Prof. Juan Jorge Michel Fariña	Head of Bioethics and Film Department

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## THE CHAIR'S DEPARTMENTS

The Chair currently has 18 departments and is hoping to establish many more for the advancement of all Ethics matters.

### Department of WMA

**Head of Department: Prof. Yoram Blachar**

The purpose of the department is to strengthen and promote the Chair's relationships with the management of the World Medical Association (WMA) and with its members around the world.

### Department of Education

**Head of Department: Prof. Dr. Russell Dsouza**

The Department of Education aims to ensure the global spread of bioethics education. This is being achieved by continuous support and facilitation of the various bioethics units to pursue enhanced and effective local and international collaboration with intensified professional relations with academic institutions and other partners.

The Department of Education has a wide range of educational programs and courses tailored to specific populations of students of healthcare education. The department has Evidence based Faculty development program for teaching bioethics. This includes all the various disciplines in the field of medical and healthcare sciences for students – both undergraduate and postgraduate, healthcare professionals and practicing doctors in all specialties and sub-specialties. These programs empower participants addresses the challenges they face in real-life situations through acquired methodological approaches and enhance their analytical skills to recognize ethical issues that are applicable both in their clinical practice and biomedical research.

### Department of Research

**Head of Department: Prof. Rui Nunes MD, PhD**

1- Different modalities of collaborative research in the Research Department:

- a) Research projects of specific centres or institutions, although with the general oversight of the Research Department.
- b) Research projects of the Research Department that may be performed in partnership with different institutions worldwide.

2- Existing lines of research of the RD at a worldwide level:

- a) The principle of beneficence and its implications and application in medical research
- b) Autonomy and dignity in medical research and practice
- c) Bioethics and human rights, forced displacement in conflict scenarios
- d) Wellness and distress in health care professionals dealing with bioethical issues in their everyday working life
- e) Gender equality



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### **PhD on Bioethics Division**

#### **Head of Department: Prof. Rui Nunes**

A PhD in Bioethics aims at advanced training in bioethics, environmental and animal ethics, and bio law. Students who complete this cycle of studies in bioethics should be able to develop scientific research in the field of bioethics and health law and guide the work of other students in this area. Indeed, it is important to train highly qualified professionals in the field of bioethics and health law in order to promote fundamental human rights and to reinvent the ethical education of health professions in the context of universally shared values. The PhD in Bioethics student must gather the necessary skills for understanding any area in Bioethics, Environmental and Animal Ethics, and Health Law. Moreover, the student must be adequately prepared to make a regular update in these areas.

The existence of a large group of PhD students in Bioethics worldwide makes it important to create an international network in this scientific area, so that synergies are promoted between high level research projects and other initiatives involving researchers from different cultures. Also, new lines of research can be promoted namely in areas of interest to low-income countries.

Therefore, the creation of a PhD on Bioethics Division of the International Chair in Bioethics sounds reasonable so that the ICB will pave the way to new forms of cooperation between different researchers and different countries. Also, this division could cooperate with the IFT (International Forum of Teachers) so that research and teaching in different units of the Chair is promoted, as this synergy is fundamental for the development of a true global bioethics.

### **Palliative Care Department**

#### **Head of Department: Prof. Rui Nunes**

In contemporary societies, palliative care represents a different perspective toward facing both death and life. A different perspective of facing death due to the excessive technological character of modern medicine has resulted in an increasing dehumanization of clinical practice and a progressive distancing of health professionals from patients and their families. Palliative care, as active and global care, requires a significant increase in the affective dimension of the patient–physician relationship to promote patient follow-up, rather than trying to overcome death. Palliative care is also a different way of looking at life. The concept includes a life with quality, life that anticipates death, and life over the long period prior to death. Hence, it is important to consider both the multi- and transdisciplinary nature of palliative care and the consequent implications for professional training.

Great attention is already being given to this area of training; its teaching in medicine, nursing, psychology, and other healthcare professions is fundamental. Moreover, palliative care has expanded beyond oncology care, which defined this type of care in the strictest sense; it is now fundamental in the treatment of cardiac, neurological, renal, or other terminally ill patients. Therefore, the creation of a Palliative Care Department of the International Chair in Bioethics sounds reasonable so that the ICB promotes advance knowledge in palliative care worldwide as a human and compassionate way of approaching death and the dying person. Eventuality becoming the largest global organization on this area.

### **Department of International Forum of Teachers (IFT)**

#### **Head of Department: Prof. Sashka Popova**

The International Forum of Teachers is a department within the ICB that consists of teachers and instructors from around the world who have been accepted pursuant to the requirements of the ICB's Statutes as members of the IFT.

The main objective of the IFT is to form and activate, through global collaboration and dialogue, an organ that will function as a mechanism for the realization of the objectives and activities of the IFT as stated in the Statutes.

The organs of the IFT are the Head of the IFT, the Assembly, the Council and the Steering Committee.

Membership in IFT shall be open to all who have graduated from a university or equivalent academic institution, who are or were involved in teaching, instruction and guidance of bioethics, medical ethics or health law, and who are interested in fulfilling the goals and aims of the IFT and the ICB.

The IFT achieves its aims by co-operation among its members, facilitating exchange of experience and information of programs and projects. initiating and organizing the Assembly and meetings during the conferences and world congresses of the Chair.

### **Department of The Monthly Case**

#### **Head of Department: Dr. María Tormo Domínguez**

The department aims to disseminate the discipline of bioethics among physicians and healthcare professionals. The practice of medicine is and will continue to be increasingly complex, which is why health professionals must have sufficient knowledge of bioethics in order to approach and resolve ethical conflicts accordingly.

The Department's case studies are intended to be a simple and useful training tool to help doctors and healthcare professionals in their daily practice. They are provided with a better understanding of bioethics and how it can contribute to improved doctor-patient relationships.

The main activities carried out by the department are as follows:

- Develop practical bioethics case studies.
- Disseminate these cases to healthcare professionals around the world.
- Participate in scientific bioethics forums to publicize their work.

The department ensures that cases are useful for all healthcare professionals regardless of their country of origin. The department focuses on bioethical problems that have a general application. The case studies are short to facilitate their reading and keep them engaging. The most important conflicts, their possible solutions, and various alternatives are highlighted. The cases are designated to be applicable in all countries with respect to their individual laws and regulations.

### **Department of Behavioral Bioethics**

#### **Head of Department: Prof. Daniella Keidar**

Innovative technology penetrates into every area of our lives and sets our social and personal agendas.

It seems that the center of gravity in social conduct is increasingly shifting to technology, to the point of sustaining its own "life", pushing the individual, the human, to the margins. Man's basic and elementary needs for human contact and unmediated social connection are being harmed, and this has dramatic short-term, long-term and cumulative consequences.

The Department of Behavioral Bioethics will deal with this important connection and the reciprocal implications between bioethics and human behavior. It intends to fill an increasing gap in this area, hoping to illuminate and improve insights on the one hand, and suggest courses of action for improvement on the other.

### **Objectives:**

- Conduct research in the field
- Contribute to the knowledge enrichment in the field and its dissemination around the world, publish articles, information and instruction booklets to help advance the subject, the ICB and the department
- Conduct workshops and seminars in the field

### **Department of Bioethics and the Holocaust**

**Heads of Department: Dr. Tessa Chelouche M.D. & Dr. Stacy Gallin, DMH.**

The goal of the department is to bring together an international group of students and professionals to collaborate on the development of a variety of tools for educating undergraduates, graduates and professionals in the field of healthcare regarding the continuing relevance of bioethics and the Holocaust for current issues in society pertaining to medical practice, public policy and human rights. The learning about bioethics and the Holocaust can serve to connect the past, present and future; promote justice, equality, and human dignity, and foster ethical decision-making and practice.

The department achieves these goals by:

- Ensuring the use of the Casebook on Bioethics and the Holocaust at healthcare professions institutions of higher learning worldwide by translating into as many languages as possible
- Collaborating with the ICB Department of Education to offer webinars, lectures and courses on bioethics and the Holocaust to international medical, nursing and pharmacy students and professionals
- Leading global initiatives such as the Lancet Commission on Medicine and the Holocaust that aim to revolutionize education on this topic
- Developing partnerships with internationally recognized organizations, such as the USC Shoah Foundation, to develop accessible, multi-media curriculum that can be utilized throughout the world
- Creating unique programming accredited for international Continuing Medical Education credits such as, "Medicine and Morality: Lessons from the Holocaust and COVID-19," a Holocaust Remembrance Day event that brings together internationally renowned scholars in Holocaust education and bioethics.
- Developing projects with religious organizations, such as the Greek Orthodox Church, which seek to bring together members of different religious, cultural, and generational backgrounds to teach them about the importance of learning about the Holocaust and its contemporary relevance for all aspects of society.

### **The International Journal: GLOBAL BIOETHICS ENQUIRY**

**Editor in Chief: Prof. Dr. Russell D'Souza**

Global Bioethics Enquiry is a journal of the International Chair in Bioethics (ICB) and publishes reviews, original research papers, commentaries and case studies related to all issues in the field of Bioethics. Original viewpoints and narratives as well as poems in the field of bioethics are welcome. The journal also has a student section where articles in the field of bioethics written by undergraduate and postgraduate students are considered.

The Journal is indexed in: Cite Factor; National Library of Australia, Research Gate, DOAJ, Google Scholar and applied for Scopus indexation Global Bioethics Enquiry provides a platform for well-argued, well written and erudite articles on the ethical questions in medicine in the developing and developed world, bioethics as it concerns the human race, issues related to ethics and law, ethics and bioethics education, methods of teaching bioethics, bioethics in medical, nursing and allied education, international collaborative bioethical clinical research, mental health ethics, current bioethical debates and dilemmas, issues related to ageing and current medical technologies like genomics, stem cell research and artificial intelligence. The journal prefers articles that look at various bioethical issues considered in relation to concrete ethical, legal and policy perspectives and in terms of the fundamental concepts, principles and theories used in discussions of such problems and current issues.

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As medical technology continues to develop, the subject of bioethics has an impact on all those working in philosophy, medicine, law, sociology, public policy, education and related fields and also in areas like clinical research and current medical issues.

The journal has a readership that includes bioethics scholars, medical and bioethics teachers, medical nursing and allied profession students and clinicians alike.

### **Department of Bioethics and Art**

#### **Head of Department: Prof. Mary Mathew**

The department had initiated the use of Art in teaching bioethics successfully in faculty development programs and in teaching of bioethics to medical and health science students at the department of education

Art and bioethics are sources of inspiration for each other. Not only does art expand its boundaries, transforming a scientific experiment into an artistic process, but also bioethics is entering a new level of research and discussion, reinforcing its creative potential through art.

The use of art as a pedagogical tool can be an innovative approach to medical and health sciences education. It can facilitate reflection, reveal a meaningful story, and explore experiences of suffering and/or compassion.

Art- whether it is a collage, a painted picture, hand-drawn, crafted out of clay, expressed through dance, tableau, or music- can connect concepts in teaching and learning in ways that cannot otherwise be achieved. Using art as a teaching tool can create a head-heart-hands experience that engages students on many levels and connects them with complex concepts in meaningful ways.

### **Department of Bioethics & Film**

#### **Head of Department: Prof. Juan Jorge Michel Fariña**

The aim of the Department is to develop an interactive data base to share audio-visual resources for teaching bioethics.

Since the beginning, cinema has promoted ethical problems. With the expansion of the film industry, these subjects have reached wider audiences, promoting interesting discussions inside and outside the academic field. Ethical problems appear in films with a double perspective. On one side, when the films propose, in an explicit way, to take to the screen contemporary ethical discussions; on the other side, when audiences and critics find in the work of art, the opportunity to discuss moral or ethical issues. In both cases, the result is an extraordinary experience of thought and action. The project aims to make an update of the available resources both aesthetics and conceptual and to systematize them for the use in academic and social projects all over the world.

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### **Scientific Literature Review Department**

#### **Head of Department: Prof. Shai Linn, MD, DrPH**

The Department routinely explores and reports resources and data for corona research. The literature is searched and selected anthology is reported in 30+ categories. Among these are data from the CDC, WHO, journals' resources and publications and leading institutions that deal with bioethics. Links to publications are given. A selected anthology offers an access to the main issues that are discussed in various publications. Periodical updating is distributed by the ICB.

### **Department of Law**

#### **Head of Department: Adv. Ilan Keidar**

The department is in the development stage. In the first phase, the department is supposed to support the Chair and guide it in legal aspects. At an advanced stage, the department is supposed to engage in research combining law and bioethics.

### **The Chair's Newsletter**

#### **Coordinator: Dr. Miroslava Vasinova & Editor-in-Chief: Dr. Giacomo Sado**

The Department of the Chair's Newsletter and Press Office were established in 2013, after the first successful experience of a Chair's standing press office during the 9th World Conference of the Chair. From that time on, in each Chair's world conference, the press office represents a lively connection center for its participants and an updated source of information, delivering daily press releases to the main national and international newspapers, and Bioethics journals.

It also collects hundreds of short interviews of the speakers that become part of the special newsletter issues dedicated to the most relevant events and pics of the conference.

The first issue of the Chair's Newsletter was born to gather only a part of the material, the ideas, the projects and, literally, the "flow of energy" coming out from each Chair's world conference. The core of the Editorial Board, headed by Dr Sado, includes Dr Alessandra Pentone, International Adviser and Dr Claudio Todesco, Technical Adviser in collaboration with several other experts. Bioethical voices, available on the Chair's website, has produced 23 issues until December 2021. Its different sections are the witness of the impressive development of the Chair all over the world, giving to experts, amateurs and beginners (even scholars and students) in the field of Bioethics a space to express themselves and to share multiple information and projects. The unique picture that, over the years, each issue offers about the multicultural expressions of the bioethical message delivered by the Chair under the lead of Professor Carmi gives us the privilege and the joy of feeling to belong to it.

### **Department of the Website**

#### **Head of Department: Prof. Daniel Fu Chang Tsai**

The IBC website provides information about the establishment of the Chair's network, the Units, the Departments, activities, publications which include the Case Book series, the Newsletter, the Global bioethics enquiry journal, etc. It aims for facilitating the connection, collaboration and dissemination of the Chair's extensive works in bioethics and law.

## **Bioethics for Youth and Children Department**

### **Head of Department: Dr. Miroslava Vasinova**

The goal of the department is to bring the message of bioethics to children and youth in various educational ways. The department focused in the early years on creating an appropriate teaching method for the younger generations. Socio-cultural tradition of ethics cannot be created in the classrooms of medical schools. The students that arrive in these classrooms carry on their backs and in their hearts their own personal history. This history consists of values that they have adopted from their earliest years in their families, in their social environments, in their kindergartens and elementary schools. Education activities in the advanced stage of academic studies can be efficient if and to what extent they are brought forward by proper methodology to the younger populations.

This assumption led Prof. Carmi to consider and initiate the creation of a training programme for younger age groups. In order to realize this idea, he asked Dr. Vasinova, Head of the Italian Unit of the Chair to collect and establish in Italy a group of educators and other professionals who agreed to prepare a book on bioethics for children and adolescents. This book is based primarily on the educational methodology of the International Chair in Bioethics. In addition, the authors were asked to create teaching tools tailored to different age groups. The Editorial Board included Prof. L. Mellilo, Dr. A. Pentone, C. Todesco, A. Traversa and H. Carmi.

The book refers to several ethical principles that are taken from the Universal Declaration on Bioethics and Human Rights of UNESCO. The book refers to four separate groups and offers diverse instructional materials to each age group. The book is written for teachers and educators. It includes materials (stories and games), and methodological explanations for its use.

The Department has published a second edition that added new parts written by authors from different countries. The first books were translated into many languages. The department plans to publish additional books and holds courses that prepare teachers and kindergarteners for extensive use of books in their institutions.

## **Department of World Bioethics Day**

### **Head of Department: Prof. Arora Praveen**

#### **Background:**

International World Bioethics Day Committee was constituted by Professor Amnon Carmi after the 11th World Conference of UNESCO Chair in Bioethics, Haifa (now International Chair in Bioethics (ICB), WMA Collaborating Centre) in Naples, Italy. In this Conference during the General Assembly of Heads of Units, on 19th October 2015, Prof. Amnon Carmi, Head of then UNESCO Chair in Bioethics, Haifa shared his dream project and proposed to celebrate one day in a year to foster the principles of Bioethics. It was suggested to celebrate World Bioethics Day on the date on which in 2005, UNESCO adopted the 'Universal Declaration on Bioethics and Human Rights' that is, 19th October. It was unanimously agreed upon by the General Assembly to celebrate World Bioethics Day on 19th October every year, starting from 2016. The Committee was constituted to coordinate the program among Chair's Units worldwide.

#### **Activities:**

Since then, the Steering Committee of the World Bioethics Day Department, chaired by Dr. Praveen Arora, has coordinated six World Bioethics Day celebrations across the world among Chair's Units. In the year 2017, the department introduced international competitions for students' wings of the Units in four categories viz. artistic posters, photography, scientific posters, and short films. These competitions witnessed enthusiastic participation by students from across the world. The poem writing competitive category was introduced in the year 2021, which received enormous participation by the students. In this year, international competitions for students' associations were also introduced in collaboration with the Department of Education of ICB. The winning entries were published in the official newsletter of the Chair 'Bioethical Voices' to inspire the students.



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**Vision:**

The department envisions to foster and maximize the participation of students in the academic and creative activities organized on the occasion of World Bioethics Day on various bioethical principles celebrated as "Theme of The Year". The competitive activities envisage to provide a platform and encourage in-depth sensitization and expression of the students towards bioethical principles through active participation. The department plans to introduce research paper competitive category in international competitions on World Bioethics Day celebrations very soon.

## HEADS OF BIOETHICS UNITS

Afghanistan / Kandahar: Dr. Noor Khaliq Noor  
Albania / Tirana: Dr. Altin Stafa  
Argentina / Chilecito: Dra. Mariana M. Varas  
Argentina / Favaloro University Buenos Aires: Prof. Dr. Francisco R. Klein  
Argentina / Ibis Program Buenos Aires: Prof. Juan Jorge Michel Farina  
Argentina / Maimonidas University: Prof. Gustavo Tafet  
Argentina / National University of San Luis: Dra. Ruth Alejandra Taborda  
Argentina / San Isidro: Dr. Daniel Lopez Rosetti  
Argentina / University of Buenos Aires: Prof. Moty Benyakar  
Argentina / University of Moron: Dr. Enrique Mario Novelli  
Armenia / Yerevan: Dr. Davtyan Susanna  
Australia / Melbourne: Dr. Theong Ho Low  
Austria / Innsbruck: Prof. Gabriele Werner-Felmayer  
Azerbaijan / Baku: Prof. Dr. Vugar Mammadov  
Belgium / Ghent: Dr. Sigrid Sterckx  
Bosnia-Herzegovina / Banja Luka: Prof. Dr. Igor Milinkovic  
Bosnia-Herzegovina / Sarajevo: Prof. Dr. Sabina Semiz  
Brazil / Centro Belo: Dr. Jesus de Almeida Fernanades  
Brazil / Conselho Regional Paraiba: Dr. Joao Goncalves de Medeiros Filho  
Brazil / Espírito Santo: Dr. Celso Murad  
Brazil / Famaz: Prof. Adriana Leticia Barbosa dos Santos  
Brazil / Federal University of Parana: Dr. Pedro de Paula Filho and Prof. Gerson Zafalon Martins  
Brazil / Hospital Das Clinicas: Dr. Chin An Lin  
Brazil / Lavras: Dr. Gustavo Ribeiro  
Brazil / Manaus: Prof. Dr. Edson de Oliveira Andrade  
Brazil / Mato Grosso: Dr. Dalva Alves das Neves  
Brazil / Minas: Prof. Antonio Angelo Rocha  
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Colombia / Villavivencio: Dr. Gina Lorena Garcia Martinez  
Congo / Bugavu: Prof. Bagendabanga Macece Eloi  
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Croatia / Zagreb: Suncana Roksandic Vidlicka  
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Cyprus / Limassol: Prof. Andrie Panayiotou  
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France / Nancy: Prof. Henry Coudane and Doyen Honoraire  
Gabon / Libreville: Prof. Pierre Dominique Nzini  
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India / Annammal: Dr. Austin Jayalal  
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India / Bathinda Punjab: Prof. R.G. Saini  
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India / Co-operative Medical College Kochi - Kerala: Prof. Dinesh Narayanan  
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India / GSMC Seth KEM. Mumbai: Dr Mariya Jiandani  
India / Haryana State Rohtak: Prof. Dr. O.P. Kalra  
India / IMA National Unit New Delhi: Prof. Dr. R. Wankhedkar  
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India / Karpaga Vinayaga: Prof. Sufala Sunil Vishwasrao  
India / Kerala Gov. University Thrissur: Dr. MKC Nair  
India / Lokmanya Tilak Sion, Mumbai: Dr. Mangesh Lone  
India / Ludhiana: Prof. Clarence J. Samuel  
India / Lucknow: Prof. Ravi Kant  
India / Madurai VELAMMAL Medical College: Prof Dr. John Rajpathy  
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India / Mumbai: Dr. Anu Kant Mital  
India / Nagpur Maharashtra: Prof. Dr. Kajal Mitra  
India / Nair Dental College Mumbai: Prof. Dr. K. S. Banga  
India / National Board Examinations: Dr. Rashmi Kant Dave  
India / Nanded: Dr. C.B. Mhaske  
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India / Pravara Institute of Medical Sciences University Maharashtra: Prof Dr. S.D. Dalvi  
India / Raipur Nodal Centre Chhattisgarh State Raipu: Prof Dr G.B. Gupta  
India / Rajasthan University Jaipur: Dr. Raja Babu Panwar  
India / Salem: Dr. T.K. Ravi

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## GENERAL INFORMATION

### Conference Venue

Porto Palacio Conference Hotel, Porto Portugal

### Press Office

Dr. Giacomo Sado (next to the conference information desk)

### Social Events

#### Monday, 7 March, 2022

18:00 Get-Together Cocktail (free for all participants)

20:00 Gala Dinner, Social Evening & Folklore Performance (paid participants and by invitation only)

#### Tuesday, 8 March, 2022

Tour of Hall of Nations, Cocktails and Fork Dinner

Tour of Hall of Nations, Cocktails and Fork Dinner

19:00 Tour of Hall of Nations, Cocktails and Fork Dinner (paid participants & by invitation only)

Busses will depart from the Porto Palacio Hotel at 18:15 exactly

#### Wednesday, 9 March, 2022

Tour of Porto Winery, Wine-tasting, Cocktails and Hors d'oeuvres

19:00 Tour of Porto Winery, Wine Tasting & hors d'oeuvres (paid participants only & by invitation only)

Busses will depart from the Porto Palacio at 18:15 exactly

### Accompanying Persons

Accompanying persons can enter the social events which they have registered for only

### Certificate of Participation

A certificate of participation will be supplied upon request

### Access to Lecture Halls

Seating is on a first come, first served basis. We recommend you go to the lecture hall well before the start of the session. Safety regulations require us to limit access to the session if the room is filled to capacity. A sweater or jacket is recommended at the lecture halls as it may be cool.

### Name Badges

You are kindly required to wear your name badge to all sessions as this is your entry to sessions.

The no badge, no entry rule will apply. Badge replacements will be 25 euros.

### Important Notice

ISAS international Seminars, the Chair and the Conference Co-Presidents will not be responsible for any loss, damage, injury, accident, delay or inconvenience to any person or luggage or any other property for any reason whatsoever. They will be exempted from any liability in respect of the above.

Personal travel and health insurance is recommended.

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# **Scientific Program**



## Monday, March 7, 2022

### 10:30-11:00 Coffee Break

### 11:00-12:30 Opening Plenary Session

Masters of Ceremony: Prof Amnon Carmi & Prof Rui Nunes, Co-Presidents of the Conference

#### Video Film about Porto:

Prof Rui Nunes, Host and Co-President of the Conference

#### Welcome Greetings

Prof. Rui Nunes, Secretary General International Chair in Bioethics

Dr. Otmar Kloiber, Secretary General World Medical Association

Annabel Seeböhm, Secretary General Standing Committee of European Doctors

Dr. Miguel Guimarães, President Medical Council of Portugal

Prof. Altamiro C. Pereira, Director Faculty of Medicine University of Porto

#### Honorary Awards Ceremony:

Prof. Rui Nunes, Secretary General International Chair in Bioethics

#### Close of the Opening Session:

Prof. Natalia Oliva-Teles, National Committee of the Conference

### 12:30-13:30 Lunch Break

Porto Hall

## 13:30-15:00 Parallel Sessions

HALL A		HALL B		HALL C		HALL D	
Ethical Aspects of E-Medicine		Human Rights I (Spanish)		Holocaust I		Alcohol and Drugs I	
Chairperson: M. Gartner, Austria	Discussion on Personal Privacy of Doctors under the Background of Internet Medical Treatment <u>Suyuan Ma</u> , China Big Data and Artificial Intelligence Implications for Decision-Making in Individual and Public Health Care <u>Sergio Rego</u> , Brazil Ethical and Legal Challenges in The Context of E-health And Data Transfer <u>Daniela Brešić</u> , Belgium The Double-Edged Sword: Ethical and Privacy Implications of FemTech <u>Bethany Corbin</u> , USA Autonomy Constraints in the Internet of Health <u>Maximilian Gartner</u> , Austria	Chairpersons: J. Xavier Proenca, Portugal & M.M. Pardo-Lopez, Spain Health and New Genome Editing Techniques <u>Joaquín Jiménez González</u> , Spain The Teaching of the Bioderecho and the Digital Environment: European Project Pro Human Biolaw <u>José Ramón Salcedo Hernández</u> , Spain Law, Technology and Health: A New Paradigm Needed? <u>Maria Magnolia Pardo-Lopez</u> , Spain Legal Safeguards for the Use of Health Data within the Public Health System in Order to Improve Healthcare Quality <u>Maria Belen Andreu Martinez</u> , Spain The Interest of Third Parties in Genetic Research: Are we Owners of our Genetic Data? <u>Juan Ignacio Cerdá Messegue</u> , Spain We are ALL Immigrants: Bioethical, Medical and Religious Issues <u>Claudio Kogan</u> , USA	Chairpersons: S. Gallin, USA & T. Chelouche, Israel Medicine in the Ghetto: the Lodz Example Ethical and Health Care Services Challenges in the Dark Days of WWII <u>Yoram Sandhaus</u> , Israel Bioethics and the Holocaust: Results of an Experiential Learning Pilot Program for Medical Students and Trainees in Poland <u>Rebecca Brendel</u> , USA 'Euthanasia' in Nazi-Germany and the Doctor's Responsibility <u>Johan Stuy</u> , Belgium How Healers Became Killers: Teaching Medical Ethics through the Holocaust <u>Patricia Heberer-Rice</u> , USA The Holocaust, Human Dignity, and Health Care: Reflecting on the Past to Protect the Future <u>Stacy Gallin</u> , USA	Chairpersons: R. D'Souza, India & D. Kala Perkins, USA Links between Alcohol Consumption and Domestic Violence: Why the Europe Should Focus on Effective Alcohol Policy? <u>Monika Wilanowska</u> , Poland Hippocrates Tears: Death by Medicine <u>Deborah Kala Perkins</u> , USA Playing with Fire? Conceptual Issues in Individual Agency and (Lack of) Control in Smoking <u>Susanne Uusitalo</u> , Finland Survey on Habits Related to Alcohol Consumption in University Students: Observations and Future Perspectives <u>Stefano Di Patrizi</u> , Italy On the Importance of Acting Solidaristic to Improve Knowledge of Medications Used During Pregnancy <u>Marieke Hollestelle</u> , The Netherlands			

HALL E		HALL F		HALL G	
Bioethics: History & Future I		Autonomy I		Ethics Committees I	
Chairpersons: J. Stuy, Belgium & I. Friedmann, Austria		Chairpersons: P. Maia, Portugal & A. de Broca, France		Chairpersons: I. Duarte, Portugal & D. D'Souza, India	
Bioethics 2020: Perfect Vision or Time to Re-Focus? <u>Michelle Mullen</u> , Canada		Person-Centered Health Care and the Patient's Fundamental Rights: The Right to Full Information and the Right to Patient Decision-Making Autonomy as Embodiments of the Principle of Human Dignity <u>Isa Filipa António</u> , Portugal		Ethical Dilemmas of Second Stage Commission on Artificial Pregnancy Termination <u>Adolf Lukanovic</u> , Slovenia	
The Early Life and The Laws of Bioethics <u>Victor Joseph Steve Effa Ateba</u> , Cameroon		Parents' Opinion on the Importance of Assent in Health Care <u>Hortense Cotrim</u> , Portugal		Review on Development of Chinese Hospital Ethics Committee <u>Chun-Lian Tang</u> , China	
Principles of Bioethics in UNESCO's "Universal Declaration on Bioethics and Human Rights" (2005) <u>Mitsuyasu Kurosawa</u> , Japan		Digital Pills: Patient Autonomy Challenged in the New Era of Digital Medicine <u>Marina Morla González</u> , Spain		Clinical Ethics Concerns and Access to Clinical Ethics Services in Rural Minnesota <u>Catherine McCarty</u> , USA	
Macedonian Case of Bioethics: History & Future <u>Dejan Donev</u> , Rep. of North Macedonia		The Konomy: Autonomy which Takes Care of Relatives <u>Alain de Broca</u> , France		Ethical Challenge to Ethics Committee: A Qualitative Study <u>Paola Melis</u> , Italy	
Once Again "Engineering Life": Current Developments – Epistemological Aspects – Ethical Issues <u>Gösta Gantner</u> , Germany		Participation of the People with Disabilities in Investigation Protocols <u>José Arias Porras</u> , Costa Rica		Dealing with Ethical Challenges in Qualitative Research: An Epistemologically Consistent Proposal <u>Maria Luz Bascunan</u> , Chile	
Towards a Reconstruction of the Concept of Bioethics <u>Ferdinando Achille Insanguine Mingarro</u> , Italy		Coercion and Freedom <u>Jeffrey Bedrick</u> , USA		Challenges in Establishing an Effective Ethical Review System in Low- and Middle-Income Countries: Sudan as a Case Study <u>Shaza Abass</u> , Sudan	
		Paternalism in End-of-Life Decisions in an African Setting: Any Cause to Worry? <u>Ijeoma Angela Meka</u> , Nigeria		Ethics and Pre-Exposure Prophylaxis (PrEP) for HIV Prevention in China <u>Simin Yu</u> , China	
		Navigating the Tension Between Individual Liberty and Population Health Benefits in Public Health Nudges <u>Derek Soled</u> , USA		The Clinical Ethics Consultancy Service at Bnei-Zion at 7 Years: Empirical Insights <u>Maya Peled-Raz</u> , Israel	

Monday, March 7, 2022

## 15:00-16:30 Parallel Sessions

HALL A		HALL B		HALL C		HALL D	
Neuro-Ethics		Meaningful Youth Engagement in Ethics and Human Rights Education		Autonomy II		Informed Consent I	
Chairperson: D. Keidar, Israel	Bioethics Principles in iPSC Research: The Need for a Code of Ethics? <u>Natália Oliva-Teles</u> , Portugal The Legal Validity of Informed Consent to the Use of Neuroscientific Mind Reading <u>Timo Istaitieh</u> , Belgium Consciousness and the Ethics of Cerebral Organoid Research <u>Karola Kreitmair</u> , USA "Being Oneself" and "Losing Oneself" in the Context of Deep Brain Stimulation (DBS): Authenticity, Personality and Personal Narrative <u>Przemysław Zawadzki</u> , Poland Bioethical Dilemmas Associated with Autism Spectrum Disorders People's Care <u>Daniél de Sousa Filho</u> , Brazil The Meaning of the Concept of "Ultimate Morality" <u>Vojin Rakić</u> , Serbia	Chairperson: R. Nunes, Portugal	Human Rights for Medical Practitioners - Advanced Training in Human Rights and Ethical Principles in Clinical Settings <u>Mahmood Abdulameer</u> , Iraq How well does Medical Education address Discrimination in Healthcare? <u>Alaa Dafalla</u> , Sudan Promoting Research Ethics through Peer Education: An Experience from IFMSA <u>Martina Miklavcic</u> , Slovenia Bioethics: The Core of Research Education for Medical Students <u>Marc Margulan</u> , Germany Medical Students in Emergency Response: Between Obligations and Safety <u>Iris Martine Blom</u> , The Netherlands	Chairperson: P. Maia, Portugal	"Wandering in Dementia" Autonomy Vs. Safety <u>Doron Merims</u> , Israel Contradiction over Autonomy: Coexistence of Inclusion and Medicalization <u>Laura Puumala</u> , Finland Bioethics and Law / The Human Dignity in a Plural Society: Conditions and Challenges <u>Manuel da Faria</u> , Portugal Can Compulsory Hospitalization of Schizophrenics Be Justified? Schizophrenics Autonomy and Paternalistic Policy <u>Min Heo</u> , South Korea Lay Perspectives of Quality of Life in Rheumatoid Arthritis Patients: The Relevance of Autonomy and Psychological Distress <u>Isabel Santos</u> , Portugal The Intensive Care as an Epistemic System: Invisibilities, Epistemic Injustice and Testimony <u>Renata Breves</u> , Brazil Autonomy of Pregnant Women in Choosing the Mode of Delivery and the Impact in Women Health: A Retrospective Study <u>Carlos Henrique Silva</u> , Brazil Tell the Cancer Pediatric Patient About His or Her Prognosis <u>Haya Raz</u> , Israel	Chairpersons: F. Rego, Portugal & R. Ekeoduru, USA	Obstetric Violence and the Birth Experience: The Role of Informed Consent <u>Jennifer Dunatoy</u> , USA A New Form for the Free and Informed Consent Terms Used in a Reference Hospital of High Complexity in Brazil <u>Maria do Carmo Lencastre</u> , Brazil Clinical Trials Involving Minors: The Role of the Ethics Consultation in Avoiding Therapeutic Misconception <u>Silvia Ceruti</u> , Italy Recent Portuguese Case Law on Informed Consent <u>Ana Carvalho</u> , Portugal Informed Consent or Scare Tactic: Ethical Implications, Challenges and Solutions for Discussion of Pediatric Anesthesia-induced Neurotoxicity Warnings <u>Rashedah Ekeoduru</u> , USA Neonatologists' Ethical Decision-making for (Non)Resuscitation of Extremely Preterm Infants: Ethical Principles, Challenges and Strategies <u>Alice Cavolo</u> , Belgium

HALL E		HALL F		HALL G	
Justice		Bioethics General I		Bioethics Education I	
Chairperson: J. Karacic, Belgium	Tackling Institutional Ageism in Healthcare <u>Tom Walker</u> , UK Covid and Prison: The Italian Experience <u>Giulia Petroni</u> , Italy P300 Wave and the Right Against Self-Incrimination: Parallel with the Evidence Obtained by DNA <u>Maria Sousa</u> , Portugal Blaming Genes and Ignoring Structures: Covid-19, Down Syndrome, and Social Determinants <u>Sara Bergtresser</u> , USA Switching Responsibility from Doctor to Patient for Informed Consent <u>Jasna Karacic</u> , Croatia The Horizon in the Establishment of the UNESCO Ethics and Religion Department <u>Yuval Cherlow</u> , Israel	Chairperson: S. Popova, Bulgaria	Patients' Rights: Limits to Justifiability and the Need for Capacity Building <u>Rita Gíao Haneke</u> , Portugal When Love Hurts: Navigating the Medical and Ethical Terrain in Advanced Dementia Care <u>Marcia Sokolowski</u> , Canada Informed Consent in Psychiatry: is the Patient Competent to Make Decisions? <u>Simona Zaami</u> , Italy Discovering my Aphasic Patient Will at the End of Life <u>Liz Nascimento</u> , Portugal Self-Ownership and the Right to Decide over One's Body in Daniel Borillo's Thought <u>Marti Colom Nicolau</u> , Spain Bioethical Aspects in the Fast-paced Biotechnologies and Innovations: Rights, Duties and Responsibilities <u>Maria Volik</u> , Ukraine Peculiarities of Teaching Bioethics in the Russian Medical University <u>Alena Donika</u> , Russia	Chairpersons: D. Cavalcanti, Brazil & G. Fortwengel, Germany	Team-Based Learning in Bioethics Education: Creating a Flexible, Low-Cost, Evidence-Based Curriculum for Trainees in Medicine <u>Sheria Wilson</u> , USA Perceptions of Medical Students about Teaching and Learning of Medical Ethics and Professionalism <u>Mohammed Abdelrahman</u> , Sudan Medical Ethics: The Digital Era <u>Gerhard Fortwengel</u> , Germany Ethics Education Role in Stem People Preparation <u>Ioannis Patis</u> , Bulgaria Ethics Education in Psychiatric Residency Training: A Resident's Perspective <u>Jessica Khan</u> , USA Bioethics Education: Developing a Bioethics, Law, and Literature Curriculum as a Means to Teach Cultural and Racial Sensitivity <u>Barbara Pfeifer Billauer</u> , Israel Promoting Patient Safety: Legal and Ethical Dilemmas <u>Vladyko Vodenicharov</u> , Bulgaria

## 16:30-17:00 Coffee Break

Monday, March 7, 2022

## 17:00-18:00 Parallel Sessions

HALL A	HALL B	HALL C	HALL D
<b>Medical Ethics: Digital Era I</b> Chairpersons: P. Camisão, Portugal & C. Boniface, New Zealand  Data Ethics Principles for Responsible Design and Trustworthy Implementation of Internet of Health Things- Enabled Telehealth Systems <u>Richard Rak</u> , Hungary  The Ethics of Online Peer Support Groups for Mental Health <u>Jordan Gorenberg</u> , UK  Informed Consent and Artificial Intelligence: An Incompatible Pair? <u>Christopher Boniface</u> , New Zealand  Health Data Ownership: Establishing the Patient as the Owner <u>Kamilla Østerberg</u> , Norway	<b>Reproduction I</b> Chairperson: N. Oliva-Teles, Portugal  Genetic Selection and Deafness: Between Irreversible Genetic Choice Made by Future Parents and State Interference in Reproductive Life <u>Carolina Rezende</u> , Brazil  Assisted Reproductive Technologies & Overpopulation <u>Chantal Patel</u> , UK  Pregnant Women and Equitable Access to Emergency Medical Treatment <u>Michael Ulrich</u> , USA  Bioethics and Alternative Forms of Pregnancy: Surrogacy, Transplantation and the Artificial Womb <u>Judit Sandor</u> , Hungary	<b>Ethics Committees II</b> Chairpersons: I. Keidar, Israel & G. Vittori Faitelli, Italy  The Clinical Trial Approval by the Ethics Committee is Enough to Guarantee Early Access to Care? <u>Giulia Vittoria Faitelli</u> , Italy  Ethical Counseling: The Impact Factor <u>Gila Yakov</u> , Israel  Engaging Bioethics Experts in the Biomedical Life Sciences Industry <u>Pol Vandenbroucke</u> , USA  The Role of Ethics Committees, Ethical and Value Driven Legislatures in the Fight Against Corruption: An Analysis of the County Assemblies in Kenya <u>Buchere Philip Brightone</u> , Kenya  Strengthening Frameworks for Post-Ebola Research Ethics Oversight in Liberia <u>Gloria T. Mason</u> , Liberia	<b>Bioethics General II</b> Chairperson: E. Protopapadakis, Greece  Sustainable Knowledge for All in the 21 Century: A Biblical Epigenetic and Linguistic Map That Connects Speech Behavior to an Invisible Scale of Nature <u>Liora Weinbach</u> , Israel  Intercultural Medicine and Plural and Democratic Society <u>Natasha Cola</u> , Italy  Ethical Best Practice in a Collaboration between an Embassy and an Offender Healthcare NGO in Advocating for their Sick Citizens Imprisoned in a Resource-Poor Western Pacific Country <u>Rachael Pickering</u> , UK
HALL E	HALL F	HALL G	
<b>Pregnancy Termination</b> Chairpersons: C. Alves, Portugal & M. Suska, Poland  Legal Discourse about Abortion in Poland: Story about Never Ending Battle? <u>Marek Suska</u> , Poland  Decriminalization of Abortion in the UK: A Survey among Doctors <u>Dermot Kearney</u> , UK  Comprehensive Decriminalization of Abortion: Legal Developments and Ethical Challenges <u>Fien De Meyer</u> , Belgium  Fetal Viability as the Abortion Threshold in The Netherlands: An Ethical Analysis <u>Lien De Proost</u> , The Netherlands	<b>Death &amp; Dying/End of Life I</b> Chairperson: D. Keidar, Israel  A Death Due to Relapsing Multiple Myeloma Complicated with Metastasis and Co-Infection with Bone Tuberculosis <u>Awa Carimo</u> , Mozambique  Euthanasia and Persons with Dementia: An Ethical Dilemma <u>Adelheid Rigo</u> , Belgium  Death and Dying - Similar or Different Perspectives in Palliative Care? <u>Alexandra Pedruco</u> , Portugal  The Gift of Death and Dying <u>Nicholas Krejci</u> , USA	<b>Medical Ethics &amp; Law I</b> Chairpersons: L. Neto, Portugal & K. Van Delm, Belgium  Physicians' Perspectives on Ethical Issues Regarding Access to Expensive Cancer Treatments: An Interview Study <u>Charlotte Bomhof</u> , The Netherlands  The Challenge of Open Science to Brain Patents and Intellectual Property Protection <u>Ashley Lawson</u> , Canada  Brain Patents in the Legal Landscape <u>Tade Matthias Spranger</u> , Germany  Accelerated Marketing Authorization of Medicines: Legal Challenges and Opportunities when Relying on Real World Data <u>Kaat Van Delm</u> , Belgium	

# Tuesday, March 8, 2022

## 08:30-10:00 Parallel Sessions

HALL A	HALL B	HALL C	HALL D
<b>Cultural Pluralism I</b> Chairperson: M. Merten, Denmark Safely Embracing Culture: The adequacy of the Cultural Safety Paradigm in Canadian and American Indigenous Healthcare <u>Eric Smith</u> , Canada Cultural Competency and Skills for Nurses: Is it a Globalization Issue? <u>Pazit Azouy</u> , Israel Multiculturalism Challenges Standardized Ethics <u>Aurohom Marmorstein</u> , USA "Medicalization": A Socio-Cultural Utilization of Medical Technologies and Practices <u>Nelta Gilboa-Feldman</u> , Israel Tackling Cultural Pluralism in Responsible Prediction <u>Mavli Mertens</u> , Denmark Ethno-Religious Assumptions in the Formation of Bioethical Epistemological Framework <u>Alan Deloitavo</u> , Canada	<b>Israel Medical Association</b> Chairpersons: R. Nunes, Portugal & J. Thome, Brazil The Doctor Who Swims Against the Current: The Ethical Approach <u>Rael Strous</u> , Israel The Doctor Who Swims Against the Current: The Legal Approach <u>Malke Borow</u> , Israel The Doctor as a Rubber Stamp: The Doctor's Ethical Dilemmas in Signing Medical Certificates <u>Yossef Walfisch</u> , Israel The Family Physician as Prophet? The Legal Implications of Fitness Certificates Issued by a Family Physician <u>Dan Rosin</u> , Israel	<b>Holocaust II</b> Chairpersons: S. Gallin, USA & T. Chelouch, Israel Child Sexual Abuse: the Holocaust, and Doctors: Ethical Responsibilities for Respectful Care <u>Beverley Chalmers</u> , Canada Bioethics and the Holocaust: Contemporary Lessons on the Body and Human Dignity <u>Dora Serug</u> , Argentina The Holocaust and the Value of the Human Corpse for Bioethics <u>Filoteos-Fotios Maroudas</u> , Greece Holocaust Doctors: The Shadows of the Past Intertwined with the Present <u>Susan Miller</u> , USA Making the History of Nazi Medicine relevant for Teaching Medical Ethics Today. Examples from the Düsseldorf Medical School Curriculum <u>Matthis Kirschel</u> , Germany Empathy, Normativity, and the Holocaust <u>Aric Hluch</u> , USA	<b>Bioethics General III</b> Chairperson: E. Oliveira, Portugal Healthcare Professionals' Wellbeing and Burnout: What Can Help and What Not? <u>Matina Maffoni</u> , Italy The Dilemma of Property Law in the Context of Human Body in the Science of Medicine <u>Jerzy Bednarski</u> , Poland Duty to Care vs. Duty to Self: Call for Guidelines for Collective Actions by Health Care Providers <u>Sharad Philip</u> , India Nurse on Nurse Bullying: Screening Failures and Hospital Liability <u>Vincent Maher</u> , USA Road Remains: Bioethical Valuations in Death <u>Flávio Rodrigo Araújo Fabres</u> , Brazil Biotechnological Risks Phenomena. From Risk Analysis to Risk Governance as a Route Towards Bioethical Maturation <u>Konstantina Mylona-Giannakakou</u> , Greece An Afrocentric Approach to CRISPR-Cas9: Considering the Ethics of Germ-line Gene Editing in the South African Context <u>Bonginkosi Shoji</u> , South Africa

HALL E	HALL F	HALL G
<b>Informed Consent II</b> Chairperson: M. Correia, Portugal Informed Consent to the Medical Treatment of Minors <u>Tomáš Doležal</u> , Czech Republic The Importance of Functional Health Literacy in the Informed, Free and Clarified Consent in Genomics <u>Ronaldo Piber</u> , Brazil The Application of the Principle of Autonomy in the Informed Consent Document for the Use of Clinical Data of the Patient <u>Adriana Ribeiro-Alves</u> , Chile	<b>End of Life I</b> Chairpersons: G. Fortwengel, Germany & B. Broeckert, Belgium Knowledge, Attitude and Practices of Healthcare Professionals in India Towards End-of-Life Care <u>Aakash Ashishkumar Setti</u> , India Vincent Lambert: Between the Right to Life and the Right to Die with Dignity <u>Sofia Santos</u> , Portugal DNR Order: What are My Boundaries? Nurses Role and Attitude <u>Samah Abdulla Al Araini</u> , Oman Advance Directives and Dementia: Self-determination, Utopia, Critical Issues <u>Carlo Pasetti</u> , Italy Attitude and Awareness about Euthanasia among the People of Thrissur, India <u>Padmakumar K</u> , India Attitudes of Belgian Muslims towards Ethical Issues at the End of Life. A Research Program (2001-2021) <u>Bert Broeckert</u> , Belgium	<b>Death and Dying I</b> Chairperson: E. Protopapadakis, Greece The Right to Die as a Hohfeldian Immunity <u>Evangelos Protopapadakis</u> , Greece Have There Been Advances in Diagnosing Death 50 Years after the Harvard Brain Death Report? <u>George Mendz</u> , Australia Dignity at the End of Life: What Can the Law Do to Achieve That Goal <u>Patrizia Bosellino</u> , Italy Orchestration of a "Good" Death: Different Perspectives on Dying in Germany <u>Andreas Walker</u> , Germany

## 10:00-10:30 Coffee Break



## 10:30-12:00 Parallel Sessions

HALL A	HALL B	HALL C	HALL D
Nursing, Law and Ethics	Bioethical Dilemmas in the Beginning of Life	Holocaust III	Bioethics Education II
<p>Chairperson: V. Martins, Portugal</p> <p>Nursing, Artificial Intelligence, Robotics, Bioethics and Law <u>Giuseppina Seppini</u>, Italy</p> <p>Should We Use Bedside Card with Patients' Medical Information in Hospital: An Ethical Dilemma in Clinical Practice <u>Xinge Zhao</u>, China</p> <p>Bioethical Principles in Emergency Nursing Practice: Value Distortion under Heavy Clinical Workload <u>Alfonso Rubio Navarro</u>, UK</p> <p>Bioethical Aspects on Medication Administration Outside Licensed Indications (off-label) in Neonatology <u>M. Dolores Rodríguez-Rabadán</u>, Spain</p>	<p>Chairperson: E. Ormari, Argentina</p> <p>Relationship Donors of Ovaries and Clinics: Medical-Administrative Devices, Biomedical Practices and Sexual and Reproductive Health <u>Consuelo Alvarez Plaza</u>, Spain</p> <p>A Comparative Analysis of Gender Expectations in Gamete Donors <u>Natasha Salome Lima</u>, Argentina</p> <p>Duel and Assisted Human Reproduction Techniques: The Psychoanalytic Clinic between Loss and New Life Construction <u>Diana Altavilla</u>, Argentina</p> <p>Parents, Children and Donors in the Bioethical Networks of the Conception by Gamete Donation <u>Elizabeth Ormari</u>, Argentina</p> <p>Bioethics: Cognitive Development, Contextual and Relational Mediators <u>Aleandra Laborda</u>, Argentina</p> <p>History of Sweden and German Eugenic's Codes; Biohipological Criteria in Latin Countries <u>Lucia Rossi</u>, Argentina</p>	<p>Chairperson: S. Gallin, USA &amp; T. Chelouché, Israel</p> <p>Holocaust Bioethics Education: Setting the Context and the Relevance <u>Ira Bedzow</u>, USA</p> <p>Teaching the Legacy of the Krankenmorde through the Prism on "Biopower" <u>Michael Robertson</u>, Australia</p> <p>Lessons from Germany: The Case of Monuments that Honor the American Doctor J. Marion Sims <u>Andrew Weinstein</u>, USA</p> <p>Medicalization of Social Policies: Nazi Roots, Contemporary Continuities <u>Amanda Caleb</u>, USA</p> <p>The Case of Inmate Physicians as a Subject in the Teaching of Medical Ethics and Beyond <u>Astrid Ley</u>, Germany</p> <p>Announcing the Lancet Commission on Medicine and the Holocaust: It's Time to Teach <u>Tessa Chelouché</u>, Israel</p>	<p>Chairpersons: I. Duarte, Portugal &amp; D. D'Souza, India</p> <p>Understanding Meaning of Non-verbal Language When Teaching and Learning a Second Language <u>Maxlene Markus-Vider</u>, Israel</p> <p>Bioethics: Knowledge and Attitudes of Medical Students (Clinical Cycle) at Buenos Aires University (Bicentral Study) <u>Gladiis Mabel Tripovich</u>, Argentina</p> <p>Quali-Quantitative analysis of Empathy Levels in Medicine Students of a Brazilian Public University: First Step of a Longitudinal Research <u>Rodrigo Melo</u>, Brazil</p> <p>A Change in the Bioethical Worldview over Fourteen Years: Analysis of Current and Future Lithuanian Teachers' Conceptions <u>Grita Skujiene</u>, Lithuania</p> <p>Challenges in Teaching Learning Process of Newly Implemented Module on Bioethics in Undergraduate Medical Curriculum in India <u>Barna Ganguly</u>, India</p> <p>Cinemeducation: A Comprehensive Approach to Bioethics Education in Health Sciences Curricula <u>Derek D'Souza</u>, India</p>
HALL E	HALL F	HALL G	
Bioethics General IV	Medical Ethics I	Human Life: Sacred Life	
<p>Chairpersons: I. Milinkovic, Bosnia and Herzegovina</p> <p>Implementation of End-of-Life Legislation <u>Rachel Nissanholtz Gannot</u>, Israel</p> <p>Study to Assess the Level of Awareness Regarding Biomedical Waste Management among Doctors <u>Logatharsan Maniarsan</u>, India</p> <p>Bioethical Issues in the Care of Patients Affected by Rare Diseases <u>Daniel López Wolf</u>, Spain</p> <p>New Technologies in Human Gene Editing: A Legal Glimpse into an Issue in a Dire Need for Guidelines <u>Tamar Gidron</u>, Israel</p> <p>Moral Arguments on Treating for Research Purposes Microbiome Data of Patients Affected by Implant Infections <u>Noemi Condit</u>, Italy</p> <p>Rights Education as an Instrument to Reduce Inequalities and to Include Disabled People in Society: Bioethical and Interdisciplinary Analysis <u>Eduardo Rala</u>, Brazil</p> <p>Philanthropic Capitalism and Global Health Policy in the Context of Bioethics <u>Ivica Kelam</u>, Croatia</p>	<p>Chairpersons: T. Johnson, UK and J. Thome, Brazil</p> <p>Dealing with Ethical Dilemmas in Geriatric Patients Through Multi-Disciplinary Team Work <u>Tammy Porat-Packer</u>, Israel</p> <p>Transplant Abuse in China and the Ethical Obligations of the Global Medical Institutions <u>Eddie Aitken</u>, Spain</p> <p>Respect of Patient's Intimacy in Physiotherapeutic Practice - Fiction or Fact? <u>Emilia Dadura</u>, Poland</p> <p>Genetic Immunization: Enhancement or Medical Intervention? <u>Tess Johnson</u>, UK</p> <p>Utilitarianism in Crisis <u>Samuel Dale</u>, Canada</p> <p>Ethical Dilemmas in Aesthetic Medicine <u>Yehuda Ullmann</u>, Israel</p>	<p>Chairpersons: H. Pereira de Melo, Portugal &amp; J. Xavier Proença, Portugal</p> <p>Quality of Life, Well-Being and Values: Subjectivist and Objectivist Approaches <u>Stelios Virvidakis</u>, Greece</p> <p>The Virtue Bioethics and Its Interface with the United Nations 2030 Agenda: Possible Dialogues with Health Promotion in Higher Education <u>Ivanti Nadir Carlotto</u>, Portugal</p> <p>Spiritual Care Program Embedded Within a Tertiary Care Hospital <u>Charles Millikan</u>, USA</p> <p>Quality of Life of the Patients with Ostomy <u>Antonio Angelo Rodham</u>, Brazil</p> <p>Does David Boonin's Desire Argument for the Wrongness of Killing Successfully Rebut Don Marquis' Future-Like-Ours Argument with Regards to the Presumptive Wrongness of Abortion? <u>Cameron Joseph</u>, South Africa</p>	



## 12:00-13:30 Parallel Sessions

HALL A	HALL B	HALL C	HALL D
Medical Law I	Medical Ethics: Digital Era II	Ethics Education: Tools and Methods I	Genetics: Ethical Aspects I
<p>Chairpersons:</p> <p>C. An Lin, Brazil &amp; I. Milinkovic, Bosnia and Herzegovina</p> <p>Voluntary Sterilization as a New Formula of Contraception of the 21st Century? The Admissibility of a Voluntary Deprivation of Procreation Ability: Comparative Law <u>Dorota Frankowska</u>, Poland</p> <p>Mandatory or Voluntary Vaccination? Functioning and Effectiveness of the Legal Regulations Concerning Preventive Vaccination in Selected European Countries <u>Sebastian Czechowicz</u>, Poland</p> <p>Whistleblowing in Healthcare Sector in Bosnia and Herzegovina: Legal and Ethical Issues <u>Igor Milinkovic</u>, Bosnia and Herzegovina</p> <p>Making Sense of Public Interest in Healthcare and Health-related Research: An Ethico-legal Analysis <u>Zlata Jaffer</u>, UK</p> <p>Just Culture and Medical Law: Professional Ethics, Safety and Accountability <u>Carolina Rius Alarcó</u>, Spain</p> <p>Commercialization of germ cell donation in the Czech Republic <u>Jakub Valc</u>, Czech Republic</p>	<p>Chairpersons:</p> <p>R. Parsa-Parsi, Germany &amp; A. Menyhard, Hungary</p> <p>Let's Talk About Sex. [Robots] <u>Llona Kavege</u>, USA</p> <p>Consulting "Dr. Google": How the Digital Search for Internet Health Information Influences Doctor-patient Relationship <u>Ricardo Arruda</u>, Brazil</p> <p>A Critical Perspective on the Transparency Issue of the Medical Implementation of Artificial Intelligence <u>Banu Buruk</u>, Turkey</p> <p>Social Media and the Impacts on Medical Behavior and Patient Doctor Relationship in Taiwan: From the View of the Medical Doctors <u>Jack Iien-Yu Huang</u>, Taiwan</p> <p>Data Economy in the Health Care Sector <u>Attila Menyhard</u>, Hungary</p> <p>What's Up, (Robo)Doc? Uniting the Nations of Artificial Intelligence: Medical Law and Ethics <u>Rory O'Sullivan-Hennessy</u>, Ireland</p>	<p>Chairpersons:</p> <p>S. Mendonca, Portugal &amp; V. Carlson-Ohlers, USA</p> <p>Short-Term International Humanitarian Missions: Results of a Research Study <u>Patrick Jung</u>, USA</p> <p>Short-term International Humanitarian Missions: The Scholarly Debate <u>Victoria Carlson-Ohlers</u>, USA</p> <p>Experience of Moral Case Deliberation as a Regular Clinical Practice in a Teaching Hospital of Taiwan <u>Hung-Yang Tao</u>, Taiwan</p> <p>Moral Friendship as the Cultivation of Moral Taste and Judgment in Professional Life <u>Jon Borowicz</u>, USA</p> <p>Ethics Laboratory: An Important Applied Ethics Experience <u>Keine Batista Alves</u>, Brazil</p> <p>Mental Health Literacy and the Stigma of Mental Illness in European High School Students <u>Ana Guerrero Gomez</u>, Italy</p>	<p>Chairpersons:</p> <p>N. Oliva-Teles, Portugal &amp; A. Cassiers, Belgium</p> <p>Human Germline Gene Editing: Did Jiankui He's Experiment Open Pandora's Box? Critical Issues and Future Perspectives <u>Sara Bonomelli</u>, Italy</p> <p>Ethical Problems of Preimplantation Genetic Diagnosis <u>Elena Grebenshchikova</u>, Russia</p> <p>30 Years on from the Establishment of the Human Fertilization and Embryology Authority (IVF regulator) in the United Kingdom: Is it Now Time for a Broader, Bolder Regulator to Address Issues of Genetics, Commercial Genomics and Big Data? <u>Gemma Hobcraft</u>, UK</p> <p>Changing our Moral Dispositions: An Assault on Identity? <u>Jennifer Gulho</u>, Canada</p> <p>Ethics Committees, the Right to Health and the Right to Benefit from Scientific Progress <u>Didier Coeurnel</u>, Belgium</p> <p>Conflicting Rights and Interests in Reproductive Choices: When Parents Want to Choose the Genetic Characteristics of Their Child <u>Aurèle Cassiers</u>, Belgium</p>

HALL E	HALL F	HALL G
Discrimination	Human Dignity	Bioethics-General V
<p>Chairpersons:</p> <p>H. Pereira De Melo, Portugal &amp; U. Suryadevara, USA</p> <p>Rethinking Vulnerability in the Presence of Disability: Challenges or New Possibilities? <u>Martina Vuk</u>, Switzerland</p> <p>Hearing the Unheard: Testimonial Injustice in Clinical Pain Management <u>Claire Moore</u>, USA</p> <p>"Universal" Healthcare? Disparities in Care of Indigenous Canadians <u>Riley Dickson</u>, Canada</p> <p>Ethical Considerations Emerging from a Realist Synthesis of Interventions aimed at Reducing HIV-Stigma in Healthcare Settings <u>Jérôme Pelletier</u>, Canada</p> <p>Access to Healthcare for the Immigrant Population is an Ethical Minimum <u>Sandra Lopes Aparício</u>, Portugal</p> <p>Stigma related to mental illness and added burden of COVID-19 in older adults: The Problem and Possible Solutions <u>Uma Suryadevara</u>, USA</p>	<p>Chairperson:</p> <p>J. Thome, Brazil</p> <p>Corrective Ethics in the Mid-Century Practice of Separating Twins at Birth <u>Adam Kelmenson</u>, Hong Kong</p> <p>Historical Approach to Children during the First 1000 Days of Life and Its Implications on Contemporary Bioethical Debate <u>Bianka Gabric</u>, Italy</p> <p>Plea for the End of a Name without Respect: A Proposal from an Association of Mental Health Professionals in Cameroon <u>Emmanuel Richard Dipoko Dibotto</u>, Cameroon</p> <p>Person or Merchandise? Protecting Human Dignity and the Environment <u>Henrique Souza</u>, Brazil</p> <p>Article 8 of the ECHR, Human Dignity and the Disposal of the Human Body and its Parts <u>Neil Maddox</u>, Ireland</p> <p>Bioethical and Legal Challenges of Legal Personality <u>Stela Barbas</u>, Portugal</p>	<p>Chairperson:</p> <p>E. Oliveira, Portugal</p> <p>COVID-19 and Alternative Medicine: The Case of African Traditional Medicine <u>Mbini Tosam Jerome</u>, Cameroon</p> <p>Reasons and Un-Moderating Sources for HPV Vaccination Hesitancy among Ultra-Orthodox Jewish Mothers <u>Miriam Bentwich</u>, Israel</p> <p>Moral Distress Among Nurses Providing End-Of-Life Care: Factors, Perceptions and Implications <u>Grace Qamar</u>, Israel</p> <p>Rawlsian Right to Abortion Access as a Case Study: Bioethics and Political Engagement <u>Danielle Pacia</u>, USA</p> <p>Food Labelling: Ethical Reflexion for an Accurate and Equitable Information <u>Gisele Kanny</u>, France</p> <p>Can Autonomy be Recognized Solely by a Legal Assertion of Patients' Rights? <u>Sophie Traiteux-Signal</u>, France</p>
<b>13:30-14:30 Lunch Break</b>		

## 14:30-16:00 Plenary Session

WMA Session: International Code of Medical Ethics  
 Chairpersons:  
 Prof. R. Nunes, Portugal & Dr. O. Kloiber, France  
 Introduction and Insights into the Process of Revising the International Code of Medical Ethics  
 Dr. Ramin Parsa-Parsi, Germany  
 Ethical Limits to a Physician's Right to Conscientious Objection?  
 Dr. Otmar Kloiber, France  
 Physician Conflicts of Interest and Intrusive Advertising  
 Tomas Hedmark, Sweden

## Porto Hall

## 16:00-16:30 Coffee Break and Poster Viewing

## 16:30-17:30 Parallel Sessions

HALL A		HALL B		HALL C		HALL D	
Medical Research I		CPME AI in Healthcare I		Children and Youth		Medical Ethics: Digital Era III	
Chairpersons: F. Maroudas, Greece & I. Kelam, Croatia	Strengthening the Other Side of the Table: Civil Society as a Prerequisite for Ethical Clinical Research <u>Klarash Atamessh</u> , USA	Chairpersons: R. Nunes, Portugal & A. Seeböhm, Belgium	Humanizing AI in Healthcare <u>Bogi Eliassen</u> , Denmark CPME Policy on Artificial Intelligence (AI) in Health Care <u>Christian Lovis</u> , Switzerland Regulating Artificial/Augmented Intelligence (AI) in Medicine and Health Care <u>Omar Kloiber</u> , France	Chairperson: M. Vasinova, Italy	Children and Youth Bioethics Education <u>Alessandra Pentone</u> - European Centre for Bioethics and quality of Life, Italy How to Teach? <u>Miroslava Vasinova &amp; Antonella Mauri</u> - European Centre for Bioethics and Quality of Life, Italy Artistic Interpretation of Bioethics Subjects <u>Antonella Mauri &amp; Miroslava Vasinova</u> - European Cobra for Bioethics and Quality of Life, Italy	Chairperson: F. Rego, Portugal	AI in Healthcare: An Ethical Analysis of the New Paradigm <u>Perihan Elif Ekmekci</u> , Turkey Telemedicine, Access to Health and Medical Autonomy: A Brazilian Case Report <u>Andrey Oliveira da Cruz</u> , Brazil Telemedicine in Indonesia <u>Mohammad Baharuddin Hasanuddin</u> , Indonesia WhatsApp Application as an Informal Telemedicine Platform <u>Yonatan Goffer</u> , Israel

HALL E		HALL F		HALL G	
Bioethics General VI		Ethics Education: Tools and Methods II		Organ Transplantation I	
Chairpersons: I. Duarte, Portugal & C. Patel, UK	At the Bedside: Implementing the Concept of Shared Decision Making <u>Miriam Piven Cotler</u> , USA Ethical Challenges Encountered by Health Care Professionals Participating in Medical Humanitarian Aid Work: Summary of 25 Years of Experience of International "Save a Child's Heart" Activity <u>Anat Engel</u> , Israel The Power of Stories: Do They Even Need to Be True? A Case Presentation <u>Stephen Offord</u> , USA The Future of Human Germline Genome Editing: Legal Aspects <u>Julia Stanek</u> , Poland	Chairperson: S. Mendonca, Portugal	The Jam Session Format for the Clinical Ethical Training of Residents <u>Anna De Benedictis</u> , Italy Fritz Jahr and Bioethics of Sport: Two Distinctive Implications <u>Matija Mato Škebić</u> , Croatia	Chairpersons: R. Cañete Villafraña, Cuba & L. Zibar, Croatia	Organ Donation between Family Members: Ethical and Moral Dilemmas <u>Oded Gornij</u> , Israel Vigilance about Possible Organ Trade in Living Donor's Kidney Transplantation <u>Lada Zibar</u> , Croatia Organ Donation: Should a Presumed Consent be Sufficiently Informed? <u>Kartina Choong</u> , UK Organ Trafficking: The Portuguese Experience in Developing a Legal Framework and a Code of Conduct for Healthcare Professionals for the Management of Patients and Report Suspected Cases to Law Enforcement Authorities <u>Ana Pires Silva</u> , Portugal

# Wednesday, March 9, 2022

## 08:30-10:00 Parallel Sessions

HALL A		HALL B		HALL C		HALL D	
<b>Genetics: Ethical Aspects II</b>		<b>Organ Transplantation II</b>		<b>Medical Ethics II</b>		<b>Assisted Suicide</b>	
Chairperson: R. D'Souza, India & S. Morberg Jämterud, Sweden		Chairperson: S. Barbas, Portugal & D. Avsec, Slovenia		Chairperson: L. Bruce, USA		Chairperson: I. Duarte, Portugal	
The Ethical Debate on Human Germline Editing <u>Gabriele Werner-Felmayer</u> , Austria Public Perception of Genetic Engineering: A Systematic Review of Questionnaire Studies Pre- and Post-CRISPR <u>Pedro Ramos</u> , Portugal GPs' Views and Experiences on Population-based Preconception Expanded Carrier Screening in the Netherlands: An Empirical Bioethical Study <u>Sofia Morberg Jämterud</u> , Sweden Inside the Violence: Nature and Incidence of Family Homicides in Central Italy from 2000 To 2021 <u>Gabriele Giuga</u> , Italy The Ethics of Tissue Engineering for Regenerative Purposes: A Systematic Review <u>Anne-Floor De Kater</u> , The Netherlands		Living Organ Donation: Young Donors, Kidney "Voucher", Euthanasia Candidate as a Living Organ Donator <u>Jadranka Buturovic-Ponikvar</u> , Slovenia Ethics and the International Dimension of Organ Trafficking <u>David Matas</u> , Canada Uterus Transplants in Europe: Ethical and Regulatory Implications <u>Martyna Laszewska-Hellriegel</u> , Poland Education on Organ Donation and Transplantation: Ethical Dilemmas <u>Danica Avsec</u> , Slovenia Utilizing Personal Affinity and Identification to Increase Living Kidney Donation <u>Ira Brody</u> , USA		Ethical Management of Incidental Findings in Emergency Care: A Critical Interpretive Literature Review <u>Renata Iskander</u> , Canada Value of Closeness in the Context of Relations Between Physician, Patient and Close Relatives <u>Marlena Drapalska-Grochowiec</u> , Poland The First Nation-wide Study on Facing and Solving Ethical Dilemmas among Healthcare Professionals (HCPs) in Slovenia <u>Stefan Gosek</u> , Slovenia Comparative Study between Bulgarian and Foreign Medical Students Regarding Medical Ethics Education <u>Nikoleta Leventi</u> , Bulgaria The Regulation of Direct-to-Consumer Genetic Testing and Its Legal and Ethical Implications in South Africa <u>Amy Gooden</u> , South Africa Building Community Trust: An Ethical Response to Coronavirus <u>Lori Bruce</u> , USA		Seeking Help with Suicide: Addressing Our Human Need <u>Jim Damron</u> , USA Consensus Formation or Striving for an Ethical Position: The World Medical Association (WMA) and Its Stand on Physician Assisted Suicide (PAS) <u>Stephan Sahm</u> , Germany The Human Rights Framework Concerning Assisted Dying <u>Sien Loos</u> , Belgium Physician Assisted Suicide: Understanding the Re-instated Framework in Germany and its Rationales: A Template for the International Discourse? <u>M. Wulf Stratling</u> , UK Redefining Assisted Suicide and Euthanasia to Prevent Discrimination and to Better Align with the Goals of Patient-centered Medicine <u>Erica Ronning</u> , USA Blue Circle: Not be Afraid of his Death <u>Georges Cristini</u> , France	

HALL E		HALL F		HALL G	
<b>Patient's Right</b>		<b>Law and Ethics I</b>		<b>Bioethics General VII</b>	
Chairperson: B. Garcia Camino, Mexico		Chairperson: M. Zenelaj, Kosovo		Chairperson: G. Rego, Portugal	
Patient's Rights: A Global Care for all the Family Inside and Outside the Hospital <u>Lucia Celesti</u> , Italy Does Anonymous Data Always Cause No Harm? A Case Concerning the Legality of Using a Female Patient's Identifiable Naked Photos for Advertisement <u>Huel-Chih Niu</u> , Taiwan Palliative Care: Law and Policies in Mexico <u>Bernardo Garcia Camino</u> , Mexico Privacy and Autonomy: A Comparative Case Analysis of Medical Ethical Dilemmas in China and the United States <u>Hui Zhang</u> , China Solidarity and the Quest for a Cure - Lessons from the LaFora Body Disease Network <u>Lynette Martins</u> , USA Assessment of Psychiatric Disorders in Actions Against Social Security Inss in Federal Court of São José Dos Campos, São Paulo <u>Marcia Gonçalves</u> , Brazil		Psychiatric Clinic as a Setting for Clinical Ethics Consultations <u>Dragana Ignjatovic Ristic</u> , Serbia Prevalence of Death in Kosovo Mental Health Institutions, Ethical Challenges: Case Study <u>Miftar Zenelaj</u> , Kosovo Rethinking Informed Consent? The Metaphysical and Ethical Implications of the Placebo Effect for Clinical Approaches to Depression <u>Jonah Goldmat</u> , USA New Human Rights in The Age of Neurotechnology <u>Cleber Santos</u> , Portugal The Ethical Dilemmas of Psychotherapy Supervision: Autonomy, Privacy and Power Differentials <u>Simon Shimson Rubin</u> , Israel Ethics and Nursing in a Wired World <u>Becky Isarfat</u> , Israel		Attitudes of College Students in Kosovo about Physician-Assisted Suicide: The Influence of Personality Traits, Self-esteem, Depression and Suicidality <u>Naim Fataj</u> , Kosovo The Italian Bioethical Debate on Assisted Suicide and its Undue Equivalences <u>Francesca Marini</u> , Italy Telehealth and the Opportunity to Enhance Patient Health Literacy <u>Lukas Chandler</u> , USA Applied Ethics on Biomedical Engineering: Results of an Italian Project <u>Emanuela Midolo</u> , Italy The Communication of Death and the Care Challenges <u>Marileise Roberta Antonelli Fonseca</u> , Brazil Dealing with a Minor's Ethical and Medical Dilemma That Demand Not Reporting her Parents about her Abortion and Making Decision According to the Seven-Step Model <u>Helen Malka-Zeevi</u> , Israel Shared Decision-Making Model and Resignification as a Strategy for Bioethics Consulting <u>Paula Prieto Martinez</u> , Colombia	

## 10:00-10:30 Coffee Break and Poster Viewing

Wednesday, March 9, 2022

## 10:30-12:00 Parallel Sessions

HALL A	HALL B	HALL C	HALL D
<b>Healthcare Services &amp; Ethics I</b>	<b>Defensive Medicine CPME II</b>	<b>Bioethics General VIII</b>	<b>Benefit and Harm I</b>
Chairperson: M. Benyakar, Argentina	Chairpersons: J. Thornton, USA & S. Das, Belgium	Chairpersons: M. Gartner, Austria & N. Rodriguez Suarez, Colombia	Chairperson: M. Correia, Portugal
Champagne Needs Lemonade Money: The use of Personal Health Budgets in the NHS <u>Deoanathi Slade</u> , UK Factors Influencing Implementation of Patients Centered Care Among Health Care Professionals: Case of Kahama Town Hospital, Shinyanga Region in Tanzania <u>Lazaro Amon Solomon Haule</u> , Tanzania How to Balance HIV Patients' Privacy and the Public's Health Safety: An Ethical Dilemma about Partner Notification <u>Wenjing Jiang</u> , China The Patient Capability of being part of a Medical Services Contract <u>Mariya Petrova</u> , Bulgaria Ethics, Deontology and Professional Responsibility as a Common Denominator for the Health Professionals <u>Laila Perciballi</u> , Italy	How to Reduce Defensive Medicine <u>Daiva Brogienė</u> , Lithuania Patient Centered Care in Non-Cancer Chronic Pain <u>Catarina Matias</u> , Portugal Sustainability in Healthcare: Choosing Wisely Norway as a National Voice Against Medical Overuse <u>Stefan Hjordtsson</u> , Norway	Stakeholders Involvement in Developing an Organizational Code of Ethics in a Hospital Network <u>Yossi Weiss</u> , Israel Perception of Physicians Regarding Mental Health Care in Primary Health Care in Poços De Caldas City, Brazil: <u>Euclides Colaco Melo Dos Passos</u> , Brazil Proposal for Hierarchy for Bioethics Consulting <u>Nathalia Rodriguez Suárez</u> , Colombia Global Health Ethics: A Study on Self-experimentation in Emergency Contexts <u>Tania Manriquez Roa</u> , Switzerland Bioethics of Disability <u>Ruth Zafran</u> , Israel Ethical Precepts in Animal Testing in Brazil and Portugal <u>Mario Ivo Serinolli</u> , Brazil	Study Case2019: A Flight Attendant Dies after being Infected by Measles during a Flight: Who is Responsible? An Ethical, Legal and Medical Discussion <u>Tamar Katz Peled</u> , Israel Compassion in Medical Treatment-Jewish Medical Ethics <u>Yehiel Kaplan</u> , Israel Experience of Organ Donation Drive in Urban India <u>Shailaja Mane</u> , India Risks and Challenges in Diagnosing <u>Antonia Sahm</u> , Germany Against Pandemic: Institutional Responses between Freedom and Authoritative Instances, Ethical and Legal Analysis of the Italian Pandemic Plan 2021-2023 <u>Lorena Forni</u> , Italy Genetic Data: Is There a Right to Oblivion? <u>Mónica Correia</u> , Portugal
HALL E	HALL F	HALL G	
<b>Medical Ethics III</b>	<b>Environment Ethics</b>	<b>Veterinary, Medical &amp; Animal Research Ethics</b>	
Chairperson: R. Parsa-Parsi, Germany	Chairperson: M. Puumala, Finland	Chairperson: A. Olsson, Portugal	
Due to the Aspect of Distribution Justice: Is the Discussion of a Potential Therapy in Very Rare Diseases Justifiable? A Lesson from Paediatrics Juergen Brunner, Austria "Giancarlo Rastelli" Clinical Ethics Service <u>Luigi Zucaro</u> , Italy Secondary Use of Health Data for Precision Medicine <u>Chih-hsing Ho</u> , Taiwan Morality and Personality <u>Daniijela Trosavljević</u> , Serbia Abuse of Procedural Right as a Doctors' Rights Protection Measure in the Light of Recent Changes in The Polish Legal System <u>Hanna Matyja</u> , Poland	Mehusgan NGO: A Revolution in Community Standards for Social Immunity and Public Health Advocacy <u>Meir Ezra-Elia</u> , Israel The New Harms of Environmental and Health-related Choices <u>Mikko Puumala</u> , Finland Corporate Sustainability: Making the Planet a Better Place for Our Children <u>Dorothy Koeh</u> , Kenya Exploring the juridical Dimensions of One Health through Bio Law <u>Pablo Serra-Palao</u> , Spain Biodiversity Loss as an Intergenerational Problem <u>Blanca Soro Mateo</u> , Spain	Developing a New Code of Conduct for the Veterinary Profession in Portugal: Insights from a Collaborative Study <u>Manuel Magalhães-Sant'Ana</u> , Portugal Veterinarian Moral Distress: Ethical and Legal Issues of Euthanasia <u>Annalisa Di Mauro</u> , Italy Cui bono? Experiments on Animals in the Light of the Activity of Ethical Committees in Poland <u>Agata Strzadala</u> , Poland Animal and Science: An Incomprehension Story <u>Virtudes Azpitarte</u> , Spain	



Wednesday, March 9, 2022

## 12:00-13:30 Parallel Sessions

HALL A		HALL B		HALL C	HALL D
<b>Genetics: Ethical Aspects III</b>		<b>Medical Errors and Human Dignity</b>		<b>Medical Ethics IV</b>	<b>Bioethics-General IX</b>
Chairpersons: <u>A. Vaz Mouyal</u> , UK & N. Oliva-Teles, Portugal		Chairperson: <u>G. Fortwengel</u> , Germany		Chairperson: <u>D. Misselbrook</u> , Bahrain	Chairperson: <u>M. Ramusović</u> , Serbia
Preimplantation Tests in the Light of the ECtHR's Judgment Costa and Pavan v. Italy – Between Moral and Pragmatic Issues of the Desire to Conceive a Healthy Child <u>Adriana Denys-Starzec</u> , Poland		Medical Errors Reporting Procedures: Knowledge, Perception, Recognition and Practices among Medical Residents and Senior Staff Members <u>Mira Kochanovsky</u> , Israel		Is Virtue Theory Any Use in Medical Ethics? <u>David Misselbrook</u> , Bahrain	Legal Capacity of Serbia for the Implementation of Living Wills <u>Mirza Ramusović</u> , Serbia
Predictive Genetic Testing in Huntington Disease: Ethical Dilemmas and Patient's Right to Information <u>Raluca Dumache</u> , Romania		Patient Safety Interventions Perception in Hospital Staff. Considerations Over the Influence of The Healthcare Environment and the Institutional Responsibilities <u>Francisco Klein</u> , Argentina		Day to Day Physician Work: Moral Decision Making and Administrative Awareness <u>Chen Buxbaum</u> , Israel	The Contemporary Epistemological Sensibility with Social Ethical Demand: Approaches to African-Style Bioethical Principles and Values <u>Ada Marie Françoise Asthaire</u> , Cameroon
Procreative Non-Maleficence: A South African Human Rights Perspective on Heritable Human Genome Editing <u>Donrich Thaldar</u> , South Africa		Communication and Resolution Programs (CRPs): A Growing International Movement in Healthcare Systems <u>Aaliyah Eaves</u> , USA		Health Inequity: A Tool of Political Denunciation <u>Carlos Francisco Provano</u> , Argentina	Children Vaccination Respect for Multiculturalism: Social Work Ethics <u>Adi Pachter-ALT</u> , Israel
Interoperable Data Sharing in Pediatric Genomics: The Gold Standard for Privacy and Security? <u>Vasiliki Rahimzadeh</u> , USA		Dignified Healthcare: Human Dignity as Essential Value in Regulation and Provision of Healthcare <u>Ramunė Kalėdienė</u> , Lithuania		Herd Immunity and the Ethics of Vaccination <u>Pol Cuadros Aguilera</u> , Spain	Bioethics and the Future Generation <u>Ana Claudia Ferraz</u> , Brazil
Lulu and Nana, The First Genetically Edited Babies <u>Vera Lúcia Raposo</u> , Macau China		Human Dignity for the Elderly: A Paradox <u>Debora Gozzo</u> , Brazil		CRISPR and Patents: A South African Perspective on the CRISPR Patent Landscape <u>Meshaandren Naidoo</u> , South Africa	The Ethical Object Revisited: A New Ethical Object Approach to Ethical Analysis <u>Ramon Nadres</u> , Indonesia
Jnetics: 6 years of Genetic Screening within the UK <u>Ashkenazi Jewish Population</u> <u>Alegria Vaz Mouyal</u> , UK		Research without Ethics: The Crime of the Strasbourg Skull Collection. New Evidences, New Perspectives, New Results <u>Julien Reitzenstein</u> , Germany		The Dilemma of Pandemic Triage, Lessons for the Future: Comparative Frame of Ethical and Legal Issues in Italy, Germany and Israel <u>Teresa Andreanu</u> , Italy	Creation of an Enabling Legal Environment to Ensure Rights to Access Healthcare in Nigeria <u>Oluwatamilorun Adenipekun</u> , USA

HALL E		HALL F		HALL G
Confidentiality & Informed Consent		Benefit and Harm II		Human Rights II
Chairperson: O. Kloiber, France		Chairperson: H. Coudane, France		Chairpersons: J. Xavier Proença, Portugal & S. Shahzad, Pakistan
Protected Health Information Vulnerability in Telemedicine <u>Bernard Cohen</u> , USA		The "Stop of Procedure" in Orthopedic Surgery: Causes, Legal and Ethical Outcome <u>Henry Coudane</u> , France		Does Privacy Matter if you are Dead? A Healthcare Perspective <u>Aiste Gerybaite</u> , Italy
Consent and Autonomous Vehicles <u>Eirini Darkadakis</u> , Greece		Withholding and Withdrawing Life Support Measures from Terminally Ill Patients: Perceptions of Healthcare Workers at Bugando Medical Centre, Mwanza Region-Tanzania <u>Ndakibae Gabriel Mabega</u> , Tanzania		Shift in the Paradigm for the Protection of the Human Rights of Persons Suffering Mental Illness or Psychosocial Disabilities <u>Ksenija Turkovic</u> , Croatia
Challenges in Seeking the Right, Legal and Ethical Consent for your Study/Design <u>Audrey Van Scharen</u> , Belgium		Risk-Benefit Ethical Assessment of Basket and Umbrella Trials <u>Karolina Strzebońska</u> , Poland		People with Communication Disabilities: SLTs Speak Up for Their Inclusion and Participation <u>Tiziana Rossetto</u> , Italy
Finding Value, and Values, in the Tangible: Nishida Kitaro's Pure Experience Theory <u>David Howell</u> , USA		Students in Health Sciences, Attention Danger! <u>Cathy Thiel</u> , France		Amazonian Indians: A New Genesis for Humanity? A Discussion of the Idea of Vulnerability Applied to Indigenous Minorities <u>Braulio Ines Barbosa Ribeiro</u> , UK
		From Medals to Medical Research: Justice and Stakeholder Duties in Secondary Uses of (Wada) Athlete Data <u>Rachel Thompson</u> , UK		Social Inclusion & Positive Rehabilitation of Children with Down Syndrome is Their Basic Human Right: A Thought Paper in the Contextual Environment of Pakistani Society <u>Saadia Shahzad</u> , Pakistan
				Hungry for Change: Is Big Food the New Big Tobacco and What Can Global Health Law and Ethics Do about It? <u>Citta Wladado</u> , UK
13:30-14:30 Lunch Break				

Wednesday, March 9, 2022

## 14:30-16:00 Parallel Sessions

HALL A	HALL B	HALL C	HALL D
Healthcare Services & Ethics II	Health and Gender Equality	Death and Dying II	Bioethics Education III
<p>Chairpersons: M. Puig Hernandez, Spain &amp; G. Rego, Portugal</p> <p>Applying Narrative Authority to Build Healthcare Practices to Effectively Recognize and Serve Muslim Patients, Particularly Women, in a Predominantly Non-Muslim Community <u>Fahmida Hossain</u>, USA</p> <p>Services and Cost of Medical Assistance <u>Sérgio Melo</u>, Brazil</p> <p>Immolation Predictors: Results of the STIGBATE Study in France <u>Camille Gravelier</u>, France</p> <p>Janetson's Definition of Moral Distress: A Philosophical Study <u>Alana Prasad</u>, Canada</p> <p>Cyborgs: Human Body, Technological Devices and Freedom <u>Marc-Abraham Puig Hernández</u>, Spain</p>	<p>Chairperson: J. Home, UK</p> <p>Do We Need an Ethical Discourse about Breastfeeding? <u>Lisa Rubin</u>, Israel</p> <p>Adolescents' Autonomy to Access Sexual &amp; Reproductive Health Services in Colombia: What Do Adolescents Want? And Should it Matter? <u>Julien Brisson-Morales</u>, Canada</p> <p>Female Genital Mutilation Prevention Orders: Is the Law Fit for Purpose <u>Joseph Home</u>, UK</p> <p>"Wasteland": The Ethics of Care in the Experience of Female Doctors at The Forefront of the Fight Against Covid-19 <u>Olgata Silva</u>, Brazil</p>	<p>Chairpersons: L. Teixeira, Portugal &amp; F. Rego, Portugal</p> <p>Canadian Healthcare Providers' Perspectives on using Advance Consent for Medical Assistance in Dying <u>Caroline Variat</u>, Canada</p> <p>Spiritual Advocacy in Palliative Care <u>Francisca Rego</u>, Portugal</p> <p>New Taxonomy for Prolonged Disorders of Consciousness May Help with Decisions on Withdrawal of Clinically Assisted Nutrition and Hydration: A Proposed Decision-Making Pathway <u>Liliana Teixeira</u>, Portugal</p> <p>End-of-Life Care to Patients with Advanced Dementia in Emergency Situations in Acute Hospitals: Clinical and Ethical Aspects <u>Esther-Lee Marcus</u>, Israel</p> <p>Shared Decision-Making at End-Of-Life Care for End-Stage Renal Disease Patients in Israel <u>Wassem Abu Hatoum</u>, Israel</p>	<p>Chairpersons: R. D'Souza, India &amp; V. Martins, Portugal</p> <p>Strengthening Perceptions of Ethical Competence among Nursing Students and Graduates <u>Samira Obeid</u>, Israel</p> <p>Evolution of Brazilian Bioethics after the Doctoral Program Federal Council of Medicine Agreement with the University of Porto <u>Débora Eugênia Braga Nóbrega Cavalcanti</u>, Brazil</p> <p>Bioethics Education and the Decision Making of Medical Students <u>Vera Martins</u>, Portugal</p> <p>Nursing Ethical Discussion: Is it Possible in Times of Economic and Resource Scarcity? <u>Hagar Cohen Saban</u>, Israel</p> <p>The Christensen Project: Serving the Underserved Through Psychiatry <u>Caroline Nickerson</u>, USA</p>

HALL E	HALL F	HALL G
Bioethics General X	Medical Ethics V	Genetics: Ethical Aspects IV
<p>Chairpersons: R. Parsa-Parsi, Germany &amp; D. Skaramuca, Croatia</p> <p>Artificial Intelligence in Drug Development to Bring Hope or Chaos? <u>Doris Skaramuca</u>, Croatia</p> <p>Law &amp; Literature and Bioethics <u>Caio Dib</u>, Brazil</p> <p>Patient Communication in the Digital Era: Where to Draw the Line? <u>Roopa Verghese</u>, India</p> <p>Legal Evaluation of Opportunities for a Successful Public-Private Partnership in the Polish Healthcare Sector <u>Weronika Wojturska</u>, Poland</p> <p>Bioethics of PCPNDT Act of India <u>Srikumar Vasudevan</u>, India</p> <p>Nothing About us Without us: A Disability Challenge to Bioethics <u>Sagit Mor</u>, Israel</p> <p>The Future of Genome Editing <u>Shaun Pattinson</u>, UK</p>	<p>Chairperson: C. An Lin, Brazil</p> <p>Ethics and the New Era of Genetics <u>Beata Laki</u>, Hungary</p> <p>Analysis of Gravidarum Eclampsia and Hellp Syndrome in Medical, Bioethics and Ethical Clinical Perspectives <u>Nasrudin Andi Mappawate</u>, Indonesia</p> <p>The Proximate Principle: A New Approach Towards Germline Gene Editing? A South African Perspective <u>Tamanda Kamwendo</u>, South Africa</p> <p>Caring without Borders: Transferring a Recovering Child to an Unknown Destiny <u>Naama Shahar</u>, Israel</p>	<p>Chairperson: M. Craig, Ireland</p> <p>The Human Rights of People with ID and Genetic Research <u>Maarten Otter</u>, The Netherlands</p> <p>Ethical Dilemmas Concerning Incidental or Secondary Genomic Findings <u>Vivian Coria</u>, Brazil</p> <p>Genetic Health Data and the Use of Consent Waivers...Where to from Here? <u>Margaret Craig</u>, Ireland</p> <p>Serious and Significant Genetic Condition, a Need for a Definition <u>Wair Crouch</u>, UK</p> <p>When Identity is for Sale: Genetic Ancestry Testing, Informed Consent, and Diasporic Social Justice Concerns <u>Shawneequa Callier</u>, USA</p> <p>Research on Human Germline Editing and the Freedom of Scientific Research: A South African Legal Perspective <u>Michaela Rae Steyler</u>, South Africa</p>
16:00-16:30 Coffee Break and Poster Viewing		

Wednesday, March 9, 2022

## 16:30-17:30 Parallel Sessions

HALL A		HALL B		HALL C		HALL D		
Bioethics Education IV		Law and Ethics II		Holocaust IV		Cultural Pluralism II		
Chairperson: M. Vasinova, Italy	Formal Bioethics Instruction in Saudi Medical Schools: Challenges and Solutions <u>Ruaim Muaygil</u> , Saudi Arabia Integrating UNESCO Bioethics Declaration topics into an Undergraduate Biomedical Engineering Curriculum <u>Charles Tritt</u> , USA The importance of incorporating Cultural Sensitivity in the Bioethics Education among Medical Schools: Lessons from the Asia-Pacific Region <u>Olivia Ngan</u> , Hong Kong Development and Implementation of an Institutional Curriculum in Ethics and Public Health in Cuba <u>Roberto Cañete Villafrañca</u> , Cuba Faith Stronger Than Death: Treating Jehovah's Witnesses with Blood Products <u>Luba Tachalov</u> , Israel	Chairpersons: S. Uusitalo, Finland & V. De Wankel, USA Conscientious Objection in the Nursing Profession: Limitation of Therapeutic Effort and Terminal Sedation <u>Ana Belen Sanchez-García</u> , Spain Nurses' Dignity in Palliative Care: A Focus-Group Investigation <u>Alessandro Stievano</u> , Italy Legal Mechanisms Available to Pharmaceutical Companies to Avoid their Civil Liability for Covid-19 Vaccination <u>Silvia Vilar González</u> , Spain Artificial Discrimination: How Predictive Machine Learning Algorithms Bring About Greater Potential for Mental Health Discrimination <u>Valerie De Wandel</u> , USA	Chairpersons: S. Gallin, USA & T. Chelouche, Israel Designing A Successful "Medicine and the Holocaust" Course for Medical and Graduate Students Utilizing Significant Learning <u>Ashley Fernandes</u> , USA Hans Asperger's Ward for Therapeutic Pedagogy at the Viennese University's Children's Clinic: The importance of including Pre- and Post-war Years in Holocaust Education <u>Ina Friedmann</u> , Austria Teaching Medical Students about Research Ethics and Informed Consent by Considering the Nuremberg Doctor's Trial and the Nuremberg Code <u>David Urión</u> , USA The Holocaust, Lessons for Medicine: A Way to Teach Professional Values <u>Esteban González-López</u> , Spain	Chairperson: J. Greenbrook, UK Whose Microbiome is it Anyway: The Ethics of Microbiome Ownership in Relation to Indigenous Peoples <u>Matilda Handsley-Davis</u> , Australia Striking the Mother Lode in Islamic Bioethics <u>Dilkhush Panjwani</u> , Canada The Construction of Medicolegal Alienation in Physicians Practicing in Liminal Informal Clinics Servicing Undocumented Migrant Patients <u>Josephine T.V. Greenbrook</u> , UK Ethical Conflicts Arising from Cultural Differences at the End of Life: Assisting Migrant Patients <u>Lucía Higuera Cabanes</u> , Spain				
HALL E		HALL F		HALL G				
Human Rights III		Doctor's Right		Bioethics General XI				
Chairpersons: J. J. Michel Farina, Argentina & S. Davtyan, Armenia	When Right to Food Stands in Conflict with Access to Food Restrictions Required to Manage Genetically Determined Hyperphagia: The Trouble with Prader-Willi Syndrome Under the UN CRPD <u>Maria Libura</u> , Poland "None but Ourselves Can Free Our Minds"(?) - The Contribution of Hospitals' Practices to the Responsible Development of Commercial Brain-Computer Interfaces <u>István Böröcz</u> , Belgium Violence against Women in Health Services <u>Layla Abou El Hosn Cordero da Silva</u> , Brazil	Chairperson: G. Fortwengel, Germany The Right to Conscientious Objection in Medicine and Political Disobedience in Kant and Rawls <u>Georgios Boutas</u> , Greece Illegitimate Limits on Conscientious Objection to Abortion <u>Maria Laura Malespina</u> , Perú Moral Injury in Healthcare: What is it and What Can We Do? <u>Rebecca Jeyaraj</u> , UK Inconsistency of Maternity Leave Regulation for Ministry of Health's Contractual Doctors and Midwives in Indonesia <u>Muhammad Rizky Nur Karim</u> , Australia	Chairperson: M. Ramusonić, Serbia Effective Rehabilitative Approach that Respects the Dignity of the Person in End-of-Life Care <u>Francesca Almonte Lalli</u> , Italy Global Psychiatric Access: The Problem and Possible Solutions <u>Richard Holbert</u> , USA Dignified Incarceration: Humiliation, Denials of Opportunities, and Death <u>Bryan Pilkington</u> , USA Art and Human Rights <u>Claudia González Ugalde</u> , Mexico Ethical Issues and Moral Sensitivity Among Indian Physiotherapist: A Descriptive Study <u>Poovishnu Dev</u> , India					



# Thursday, March 10, 2022

## 08:30-10:00 Parallel Sessions

HALL A		HALL B	HALL C	HALL D
Reproduction II	Bioethics Education V	Death & Dying/End of Life II	Alcohol and Drugs II	
<p>Chairperson: C. Alves, Portugal</p> <p>Is Contraception Enforceable? Ethical Dilemmas with Persistent Pregnancy Wish in a Woman with Mild Mental Disability, who was Deprived of Her Parental Rights <u>Dan Cohen</u>, The Netherlands</p> <p>A Historical Overview of Prenatal Screening and Testing Technologies Development: What Should We Learn from The Past to Face Perpetual Issues Related to Women's Choices about Prenatal Screening and Testing? <u>Panagiota Nakou</u>, UK</p> <p>Using an Implementation Research Tool to Guide the Implementation of Non-Invasive Prenatal Screening <u>Terry M. Laforce</u>, Canada</p> <p>Nothing about me without me: Ethical Aspects of Using Big Data to Improve IVF Provision <u>Orit Golad</u>, Israel</p> <p>The State of Art of Frozen Embryos's Succession in Brazil <u>Maria Carolina Nomura-Santiago</u>, Brazil</p>	<p>Chairperson: R. D'Souza, India</p> <p>Empathy Training and Bioethics in Clinical Settings <u>Eupraxia (Evri) Avlogiadi</u>, Greece</p> <p>The Cultivation of Ethical Awareness and Competence for Ethical Decision-Making for Clinical Nurses in China <u>Min Huang</u>, China</p> <p>Digital Wellbeing in Digital Bioethics: Prioritization of Bioethical Issues <u>Daniela Sotirova</u>, Bulgaria</p> <p>The Apprenticeship Model for Formation and Education of Healthcare Ethics <u>Colleen Gallagher</u>, USA</p> <p>The Ethics of Short-Term International Humanitarian Missions: Servant Leadership as an Ethical Framework <u>Megan Brock</u>, USA</p> <p>Moving from Theoretical Ethics to Applied Ethics: Management Proposal for the Police at the State of Queretaro <u>Lucero Itzel Oviedo-Rueda</u>, Mexico</p> <p>The Physiotherapist Perspective Before Ethical and Bioethical Problems Experienced in His Performance in the Family Health Support Centers (FHSC) <u>Daniela Ferraz Frauches Cavalho</u>, Brazil</p>	<p>Chairpersons: M. Ramusović, Serbia &amp; L. Ursin, Norway</p> <p>What should the Good Life for Dysphagic Elderly Patients be under Palliative Care? <u>Marcio Moreira</u>, USA</p> <p>The Impact of The Terminology on the Acceptance of Palliative Care in Breast Cancer Patients <u>Hugo Celso Pinheiro</u>, Portugal</p> <p>End-of-life Decisions in Czech Republic <u>Adam Doležal</u>, Czech Republic</p> <p>Health Inequalities and Protection of Dignity in the End of Life <u>Elmantas Peicius</u>, Lithuania</p> <p>Sticky Lives: The Ethics of Digital and Genetic Postmortality <u>Lars Ursin</u>, Norway</p> <p>Euthanasia, Assisted Suicide and Psychological Science <u>Miguel Ricou</u>, Portugal</p> <p>Euthanasia and Assisted Suicide: What is the Role of Psychologists? <u>Silvia Marina</u>, Portugal</p> <p>The Identity of Psychology in Spain <u>M. Immaculada Torres-Pérez</u>, Spain</p>	<p>Chairpersons: E. Toader, Romania &amp; P. Camisão, Portugal</p> <p>Integrating the Appreciative Dialogue in the Management of the Behavior with Risks for the Health Status <u>Elena Toader</u>, Romania</p> <p>An Ethical Framework to Manage Patient Requests for Medical Marijuana <u>Michael Redinger</u>, USA</p> <p>Medical Cannabis: Ethical Issues <u>Daniel Torres Gonçalves</u>, Portugal</p> <p>Compulsory Treatment of Pregnant Women Suffering from an Alcohol or Drugs Dependency <u>Céline Verstraete</u>, Belgium</p>	

HALL E		HALL F
Medical Ethics & Law II	Bioethics: Gender	
<p>Chairperson: G. Rego, Portugal</p> <p>Necessity of Identifying and Respecting Patients' Values: Ethical Issues <u>Thibaud Haaser</u>, France</p> <p>Non-Medical Factors Associated with Postponing Elective Operations <u>Sven Becker</u>, Germany</p> <p>Primary Decompressive Craniectomy: Decision Supported by Evidence or Overtreatment: The Ethics of Withholding this Operative Endeavor <u>Leon Levi</u>, Israel</p> <p>Developing Etiquette to Support Mentally Disabled Students in Medical School <u>Sunila Pulikal</u>, India</p> <p>Ethical and Moral Dilemma Facing Oman National Bioethics Committee <u>Ahmed Khatamy Al-Badawy</u>, Oman</p> <p>Time to Electronic Communication in Ethics Committee: Experience &amp; Challenges <u>Orit Cohen</u>, Israel</p>	<p>Chairperson: L. Teixeira, Portugal</p> <p>Non-Binary Identities: Between Pathology and Questions About the Concept of Self <u>Alexandre Silva</u>, Brazil</p> <p>Ethics, Gender and Migration <u>José Salvador Arellano-Rodríguez</u>, Mexico</p> <p>Gender Identity vs Legal Sex: Limitations in Access to Health Services: Polish and German Perspective <u>Agnieszka Bielska-Brodziak</u>, Poland</p> <p>Training in Gender Mainstreaming for Senegalese Bioethicists: Applications of a Sex and Gender Perspective in Research Ethics and Governance <u>Guillermo Martínez Pérez</u>, Spain</p> <p>City of Women: Graphism as a Tool for Effective Sexual and Reproductive Rights <u>Maria Clara Chaves</u>, Brazil</p> <p>Feminism and Gender Medicine: A Feminist Analysis of "Gender Medicine" <u>Ayelet Shai</u>, Israel</p>	

## 10:00-10:30 Coffee Break and Poster Viewing

## 10:30-12:00 Parallel Sessions

HALL A		HALL B		HALL C		HALL D	
Reproduction & Surrogacy		Medical Law II		Bioethical Discussions: The Covid-19 Pandemic		Benefit and Harm III	
Chairperson: J. Xavier Proença, Portugal		Chairperson: D. Keidar, Israel		Chairperson: L. Forni, Italy		Chairperson: E. Oliveira, Portugal	
Being a Donor has Definitely Given Me Something: An Empirical Ethics Analysis of Egg Providers' Motivations and Gains <u>Veerle Provoost</u> , Belgium		Is the "Electronic Personality" of Artificial Intelligence an Ethical Dilemma? A Reflection on the Legal Consequences of Electronic Personality for Autonomous Robots in the Field of Surgery <u>Ilina Tigatu</u> , Switzerland		Impacts of COVID-19 on EU Free Movement Law <u>Iris Goldner Lang</u> , Croatia		"If you're Gonna do it, do it Right-Right?": An Argument for Beneficence in Neurocorrection <u>Emma Dore-Horgan</u> , Ireland	
Artificial Reproductive Technology for All Women and Equality: A Question of Right or of Justice? Analysis of the French Context <u>Maroun Badr</u> , France		AI as a Medical Device: Is it Enough to Ensure Performance Transparency and Accountability? <u>Anastasija Kiseleva</u> , Belgium		Citizens' Perceptions on Ethical Issues in the Covid-19 Crisis: A Comparative Empirical Study <u>Kevin De Sabbata</u> , UK		Should Young Adolescents be Medically Circumcised to Reduce the Incidence of HIV? <u>Stuart Rennie</u> , USA	
Reproductive Biomedicine and European Public Policies: Human Genetics and Biomedical Evolution. Surrogacy: The Impact of Legislation on Medicine <u>João Xavier Proença</u> , Portugal		Bioethics and Medical Confidentiality Protection in Disaster Victim Treatments by Foreign Medical Personnel in Indonesia Reviewed from the Utilitarianism and Positivism Legal Theory <u>Diatot Dimas Achmad Andatu</u> , Indonesia		The Helsinki Committee Challenges During COVID-19 Pandemic <u>Malika Mischel</u> , Israel		Biomedical Research Involving Youth: Interrogating the Boundaries of Autonomy and Vulnerability <u>Maria Cristina Murano</u> , Italy	
Child's Rights under Surrogacy Arrangements <u>Marisa Almeida Araújo</u> , Portugal		Posthumanism as Legal Fiction and its Use for the Medical Law <u>Anna Bugajska</u> , Poland				First Comprehensive Study in Spain about Knowledge and Attitudes of the Public Towards Several Aspects of the Consent System for Organ Procurement <u>Maria Victoria Martinez Lopez</u> , Spain	
Changing Perspective on Surrogacy: An Upstream Approach <u>Paola Salomone</u> , Italy		Patient's Right to Hospital Responsibilities in Medical Dispute Resolution Reviewed from the Perspective of Vicarious Liability Theory <u>Wahyu Andrianto</u> , Indonesia				Intention of Organ Donation in an Adult Population Sample from the City of Sao Paulo <u>Angela Pecci</u> , Brazil	
Ethical Aspects of Commercial Surrogacy <u>Racheli Silvern</u> , Israel		The Need for Universal Protection of the Fundamental Rights of the Human Subject <u>Elise Roumeau</u> , France				Poachers and Gamekeepers? Misunderstandings between the Pharma Industry and Medical Ethics Committees <u>Sara Branders</u> , Belgium	
		Healthcare Care Proxy in Poland: Are the General Laws of Representation Sufficient? <u>Albert Pielak</u> , Poland					
HALL E		HALL F		HALL G			
End of Life II		Bioethics: History & Future II		Clinical Trials			
Chairperson: Miguel Ricou, Portugal & E. Pinto, Mozambique		Chairperson: M. Benyakar, Argentina		Chairpersons: C. Patel, UK & D. De Jongh, The Netherlands			
Bioethical Aspects of the End of the Life and Judicialization of Health in Brazil <u>Mirella Rebelo Bezeira</u> , Brazil		Coherence in Science Research Ethics & Policies <u>Andrea Oliveira</u> , Portugal		Assessment of Clinical Trials Localization in the U.S. and Africa as a Predictor of Global Health Disparities <u>Eric Asempah</u> , Canada			
Bland: The Omission of the Negative Act <u>Tom Smith</u> , UK		"Animals are not Machines" (Jean Meslier): A Modern Reflection on Animal Sensitivity <u>Ricardo Nogueira Solano</u> , Mexico		Clinical Trials in Developing Countries <u>Kinga Rozbicka</u> , Poland			
Palliative Care in Mozambique: Knowledge, Attitudes and Physicians' Practices in Breaking Bad News and End-of-Life Issues <u>Emilia Pinto</u> , Mozambique		European Values as Boundaries of the AI Development in the EU <u>Suncana Roksandic Vidlicka</u> , Croatia		Challenges Ahead for Ethical Assessment of Clinical Trials after Regulation (UE) 536/2014 – Case of Poland <u>Agnieszka Rabiega-Przytlecka</u> , Poland			
Medical Futility, Experimental Treatment and Best Interests <u>Lynn Kennedy</u> , UK		Teaching on the Ethics of Artificial Intelligence <u>Joseph Thornton</u> , USA		Socio-cultural Competence and People-Centered Clinical Trials: An Urgent Need for an Ethical, Effective and Collaborative International Research <u>Alessandra Pentone</u> , Italy			
Dying in Prison: A European Approach to a Dignified End of Life of Prisoners <u>Angelika Reichstein</u> , UK		Mad, Sad or Bad? <u>Digvijay Goel</u> , New Zealand		Blurred lines? On the Weight of the Purported Distinction Between Somatic and Germline Genome Editing from a Clinical Research and Regulatory Perspective <u>Carolyn Brokowski</u> , USA			
		Management: Does the Consumer Perspective Matter? <u>Agata Golawska Moody</u> , New Zealand		Ethics of First-in-Human Transplantation Trials of Bioartificial Organs <u>Dide De Jongh</u> , The Netherlands			
		Where to from Here? <u>Pratap Kovuri</u> , New Zealand					
12:00-13:00 Closing Plenary Session						Porto Hall	
Rui Nunes, Portugal							
Ilan Keidar, Israel							
Russell D'Souza, India							
Moty Benyakar, Argentina							

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## POSTER PRESENTATIONS

**8 March, 2022**

1. Benito, the 'Vaccine Child' of the Smallpox Boat  
Angel Francisco Abellan-Aleman, Spain
2. A Bioethical Discussion about the Legal Requirements for Blood Donation by Homosexual Men in Brazil  
Mario Barros Filho, Brazil
3. Bioethical Principles in the Work of Occupational Health Specialists  
Kristina Benova, Bulgaria
4. Are There Ethics, When Language is Incomplete?  
Chuckie Calsado, UK
5. Bioethics and Medical Ethics in Medical Education  
José Antonio Cordero da Silva, Brazil
6. Relationship of the Aggressor with Victims of Sexual Violence  
Evaldo Costa, Brazil
7. Informed Consent in Dentistry  
Naomi Anne Nirmala Domnic Selvam, Malaysia
8. Informed Consent on Clinical Training: Students and Teachers Perspectives  
Ivone Duarte, Portugal
9. Women with Disability: Discrimination and Recognition  
Alessandra Fabbri, Italy
10. Dismissal for Sickness Absences vs. Rights to Health and not to Be Discriminated Because of Sex  
Francisca Ferrando García, Spain
11. Ethical and Bioethical Aspects Related to Female Genital Aesthetics  
Vera Fonseca, Brazil
12. Advance Directives in Cancer Patients  
Eni Freitas, Brazil
13. Promotion of Subjective Well-Being in Older People with Dementia: Reminiscence Therapy  
Bianca Góis, Portugal
14. Quality of Life Assessment through the SF 36 Questionnaire in Elderly  
Patrícia Guedes Veran, Brazil
15. Workshop on Clinical Ethics Using "Bioethics Core Curriculum, Section 2: Study Material" by UNESCO  
Yoshimi Harada, Japan

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16. Killing the Look Out: The Unjustifiable Death Penalty for Those Not Culpable  
Megan Hoberg, USA
  17. Speak no Bias, hear no Patient, See no Color: The Mis-categorization of Racism in Healthcare  
Ashunté Hudson, USA
  18. Does Consent Correlate with Adolescence? Autonomy to Initiate Transgender Reassignment Treatment  
Miguel Ignacio Herrero, Spain
  19. Loneliness and the Effect on Health Outcomes and Quality of Life in Palliative Care Patients:  
A Scoping Review  
Fabio Ikedo, Portugal
  20. Issues in Conducting HIV Clinical Trials in India  
Pearl Kosala Raman, India
  21. Advanced Age Women: Insufficient Pensions and Need for Care  
María del Carmen López Anierte, Spain
  22. Differences in Lifestyle among Polish and Foreign Students Studying in Poland  
Michał Machul, Poland
  23. Bioethics, Euthanasia and Assisted Suicide: Normative Comparison, Regulation and Ethical  
Arguments in Several American and European States  
Luciano Maia Ferreira, Portugal
  24. Organizational Ethics in a Health Care Institution: The Experience of CISSS Chaudière-Appalaches  
Ana Marin, Canada
  25. "Here is (not) my home!" Considerations about Institutionalization and Identity of Elderly Person  
Filipa D. Marques, Portugal
  26. Bioethics in Graduation: The Importance of Deliberation on Principles and the Big Issues  
Luiz Martins, Portugal
  27. Recognizing Values and Engaging Communities Across Cultures: A Researchers Protocol  
Rakhshi Memon, UK
  28. The Refusal of Medical Treatment by Older Adults with Cancer  
Laiane Moraes Dias, Brazil
  29. Ethical Knowledge and Attitudes of Academic Community of Microbiology at National Autonomous  
University of Honduras (UNAH)  
Wendy Murillo, Honduras
  30. Conscientious Objection in the Legal Abortion Assistance  
Drauzio Oppenheimer, Brazil

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31. Is the Paternalist Conduct a Threat for Autonomy of The Patient or is it a Guaranty of The Beneficence of the Medical Conduct?  
Raphael Antonio Ovidio, Brazil
  32. Research Ethics: A Health Education Experience Involving Undergraduates and Patients at the Outpatient Clinic of a Brazilian University Hospital  
Marisa Palacios, Brazil
  33. Significance and Regulation of Ethical Review for Animal Experiment in Hospital  
Qun Pan, China
  34. Post-Mortem Pregnancy Cases in Poland  
Marta Puścion, Poland
  35. Recognize Difference to Promote Women's Education  
Marie-Alice Riault, France
  36. Justifying Abortion Laws: A Study of the National Factors Influencing Abortion Legislation  
Jasmine Jiwon Rou, Australia
  37. Respect for the Bioethical Principles of Autonomy and Justice in Medical Care in Mexico for Underaged Patients, by Implementing the Informed Consent Form  
Fernando Ruiz, Mexico
  38. What is the Role of the Local Bioethics Commission in the Proper and Successful Implementation of Scientific Research in Surgery?  
Inkar Sagatov, Kazakhstan
  39. Bioethics Challenges in Military Medicine: The Israeli Military Nursing's Experience  
Ronen Segev, Israel
  40. Corrective Ethics in the Mid-Century Practice of Separating Twins at Birth  
Malini Shanmuganathan, Malaysia
  41. A Right to Peacefully Die: Physician Aid in Dying in Dementia Patients  
Dana Shefet, USA
  42. Pregnancy with Colon Carcinoma in Medical, Bioethics and Clinical Ethics Perspectives  
Erlin Syahril, Indonesia
  43. Information, Communication and Fake News. Bioethics of Training in Public Health Service in the Digital Era  
Paola Vitale, Italy
  44. Exploring Patients' Autonomy in Cardiopulmonary Resuscitation (CPR) in Malaysia  
Hafizah Zainal Abidin, Malaysia

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## 9 March, 2022

1. Law and Ethics in the Online Sale of Medicines  
Rosalía Alfonso Sánchez, Spain
2. The Role of Human Rights in the Phenomenon of Illegal Landings: A Retrospective Study of Southern Italy  
Isabella Aquila, Italy
3. The Controversy of Initiating Artificial Nutrition in Palliative Care: Is it a Basic Human Need or a Life-Sustaining Treatment?  
Sol Benbunan, Spain
4. The Implications of Government and Public Access to a Commercial Genetic Database  
Fabiano Bianchi, Brazil
5. Collaborative Project between a Comprehensive Cancer Centre and an Ultraperipheral Regional Health Centre  
Sara Câmara, Portugal
6. Crispr-Cas9 and Gene Editing: Is the Loss of Genetic Identity the Price for Perfection?  
Fabrizio Cordasco, Italy
7. Human Rights, Global Health Policy, and Coercion in Mental Health  
Kelso Cratsley, USA
8. Ethics of a Nutrigenetic Study Focusing on Genetic Information in Lifestyle Changes  
Suchetana De, Finland
9. What Forms Should I Choose When Apply a New Clinical Study Involving Cannabis?  
Michal De-Wolff, Israel
10. Answer's Capacity and Accurate Guarantee in Evaluation Activity: Experience of an IRB in Argentina during COVID-19 Pandemic  
Maira Dolera Lembeye, Argentina
11. Suicide in Medical Students: A Local Experience  
Marco Garatti, Italy
12. Access to Health Care and Social Services for Patients Suffering from Rare Diseases in Spain  
Maria Belen Garcia-Romero, Spain
13. Teaching Clinical Ethics with Online Team-Based Learning  
Jyh-Gang Hsieh, Taiwan
14. The Concept of Duty in a Pandemic Covid-19 According to the Kantian Approach  
Eleni Karamatziani, Greece

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15. Brazilian Legislation on Ethics in Human Research and Its Applicability in Ethics Committee  
Marcelo Lima, Brazil
  16. Organ Donation in Corpses Undergoing Forensic Autopsies: The Italian Legislation and Possible Room for Further Improvement  
Martino Maesani, Italy
  17. Exploring Mental Health Patients' Perceptions and Aspirations in Employment  
Holly Melvin, UK
  18. Research Ethics Teaching: An Experience from Brazil  
Silvana Molina Lima, Brazil
  19. The relevance of an ethics committee in a higher education institution in the health area:  
The experience of ESS-P.PORTO  
Pedro Monteiro, Portugal
  20. Palliative Care is Not Always End of Life Care  
John Jeba Raj Muthiah Raj, UK
  21. Mandatory Application of Bioethical Principles and Constitutional Rights in 2019 Abortion Discussion in Ecuador  
Claudia Orellana Robalino, Ecuador
  22. Mapping of Research Ethics Committees within Health-Related Higher Education and Research Institutes -Sudan  
Shahd Osman, Sudan
  23. Disappearing Drugs: Lost, Stolen, and Discarded Medications in the Homeless Community  
Amy Reese, USA
  24. The Final Countdown: You Cannot Choose the Final Disease but You Can Select the Outcome, Euthanasia vs Palliative Care  
Victoria Rial-Plaza, Spain
  25. Ethical Aspects of the Decision to Deactivate the Implantable Cardioverter Defibrillator (ICD)  
Monica Rincon-Roncancio, Colombia
  26. Role of Multidisciplinary in Palliative Care - Case Report  
Marcia Rodrigues Bio Araujo, Brazil
  27. Descriptions of the Legal Framework of Medical Research in Norway  
Fredrik Rongved, Norway
  28. The Role of the Gerontologist in Palliative Care  
Ana Roque, Portugal
  29. Medical-Legal Aspects of the Prenatal Diagnosis: An Unresolved Topic  
Umberto Rosini, Italy



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30. The Impact of Female Genital Mutilation on Victims' Mental Health: A Review of Literature  
Matteo Antonio Sacco, Italy
  31. Work and Right to Health: Excluding Options in Present Brazil  
Vera Lucia Salerno, Brazil
  32. Terminal Sedation and Bioethics: Scenary in Italy  
Carmen Scalise, Italy
  33. Therapeutic Abandonment as a Movens for the Euthanasia Pressure  
Roberto Scendoni, Italy
  34. Environmental Bioethics: Responsibility for a Sustainable World  
Paulo Silva, Brazil
  35. Deprivation of Legal Capacity: Legal Norms and Practice in Serbia in the Light of the Human Rights Standards  
Ivana Simonović, Serbia
  36. Autonomy and Decision-making Capacity in Patients Affected by Neurocognitive Disorders  
Elena Stasi, Luxemburg
  37. Sudden Death Occurrence during Assault with Neck Compression: A Neutrally-Mediated Mechanism Induced by a Direct Vagus Nerve Compression  
Alessandro Mauro Tavone, Italy
  38. Can the Right to Therapeutic Self-Determination Justify the Assisted Suicide?  
Federica Vincenza Tiso, Italy
  39. "All of Us?" Distributive Justice Considerations in Precision Medicine Research Programs  
Kelly Turner, USA
  40. The End-of-life Choices in European States: Analysis and Comparison  
Giuseppe Vacchiano, Italy
  41. Be Right Back: The Incidence of Law on the Postmortem Scenario and the Dark Reflection of the Digital Society  
Laleska Walder, Brazil
  42. Research Integrity Education for Japanese University Students  
Akinori Yamabe, Japan
  43. Examining the Clarity of a Patient Informed Consent Form  
Agnieszka Zimmermann, Poland
  44. How are Social Stereotypes Affected by the Assisted Reproductive Process in an Artificial Uterus During the Covid-19 Pandemic Period?  
Andriana Zisimatou, Greece

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## 10 March, 2022

1. Facial Phenotyping and Deep Learning: Ethical Challenges  
Daniela Alves, Portugal
2. Ethical Aspects in Prehospital Setting  
Jordano Araújo, Brazil
3. The Moment of Diagnosis of Neuromuscular Diseases: Systematic Review  
Isabella Araujo Mota Fernandes, Brazil
4. Benefits and Risks of Bioprinting Application According to Medical Specialists' Opinion  
Desislava Bakova, Bulgaria
5. Reflections on Bioethics in Front of Environmental Issues  
Waldner Barbosa Filho, Brazil
6. Surgery for All: An Ethical Analysis of Approaches to Increasing Access to Safe Surgery in Low-Income Countries  
Anna Berman, USA
7. Ethical, Legal, and Social Implications of Post-menopausal Reproduction (PMR) in India  
Rohin Bhatt, India
8. The Privacy and Medical Records in Italy  
Sonia Bovino, Italy
9. Madam and Eve: Genetic Bimaternal Parenthood and the Enhancement of Justice  
Isabella Braga, USA
10. Waging a Continuous War: An Analysis of Pro-life and Pro-Choice Ethical Discourses  
Helena Bui, USA
11. Ghost in the Delivery Room: The Posthumous use of Adolescent Gametes by Parents  
Wendy Campbell, USA
12. From the Perspective of Spine 3D Navigation Surgery to See the Medical Law Issues Arising from Smart Medical Care  
Shiu-Jau Chen, Taiwan
13. Exploring Patients' Autonomy in Cardiopulmonary Resuscitation (CPR) in Malaysia  
Eva Costa, Portugal
14. The Ethics of Job Well Done: A Systemic Paradigm for Clinical Risk Management  
Francesco De Micco, Italy
15. Patients' Voice  
Irene Durante, Mexico

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16. Beyond Borders: Telemedicine as a Viable Treatment for Chronic HIV Therapy in Rural India  
Shafreen Fatimah, Singapore
  17. Communication of the Diagnosis of Spinal Muscular Atrophy to Children and the Principle of Autonomy  
Isabella Fernandes, Brazil
  18. Body Donation to Science: Now in Italy it is Possible  
Francesco Maria Galassi, Italy
  19. Factors Affecting Nurses' Involvement in Establishing Healthcare Policies  
Elinora Gandelman, Israel
  20. Medical Education: Patients' Perspectives on Clinical Training and Informed Consent  
Inês Gil dos Santos, Portugal
  21. Family Planning under Brazilian Law: Advances or Limits?  
Tadeu Gusmao Muritiba, Brazil
  22. Can the Carpenter Blame Their Tools: Who Holds Responsibility in Robotic Surgery?  
Jacob Howard, USA
  23. Is The Principle of Autonomy the First Principle of Medical Ethics  
Ling-Lang Huang, Taiwan
  24. Patients' Right to Different Knowledge Areas: Patient Ombudsmen's Perspective  
Saija Inkeroinen, Finland
  25. "Gestational Determinism" in the Transnational Surrogacy Industry: Exploring the Implications of Epigenetic Research on Industry Practices  
Sasha Isaac, Australia
  26. The Use of Human Cells, Tissues and Organs in Medicine: A European Legal Perspective  
Beata Kozielowicz, Poland
  27. Bad Medicine by Law: An Ethical Analysis of Healthcare Politicization in the United States  
Isabel Legarda, USA
  28. Ethical Differences between Various Forms of Physician Participation in Capital Punishment  
Mihnea Theodore Marghitu, Romania
  29. Bioethical Issues in Organ Transplantation  
Rositsa Markova, Bulgaria
  30. Opiophobia as a Barrier in Therapy of Pain: What Do Future Medical Doctors Think About?  
Branislava Medic, Serbia
  31. Technologies Versus Cognitive Enhancement: Possibilities and Limits  
Sérgio Mendonça, Portugal

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32. Assessment of Knowledge Level and Positioning on Health Ethical Prioritization: A Review  
Tatiana Menezes Garcia Cordeiro, Brazil
  33. What's Wrong with Australian Medical Health Law & the Medical Board of Australia (MBA)?  
John Myers, Australia
  34. Current Problems of Application of Medical Law in Russia and in the World  
Gulnara Nafikova, Russia
  35. Iatrogenic Splenic Rupture During a Colonoscopy without Perforation: Case Report and Medico-Legal Implications  
Margherita Pallocci, Italy
  36. Medical Liability in a Complex Case of Cardio Cerebral Ischemic Attack: A Case Report  
Pierluigi Passalacqua, Italy
  37. Presumed Post-Mortem Donors: The Degree of Information of University Students  
Rita Pinho, Portugal
  38. Global Benevolence or Self-Advancement Abroad? Rethinking the Ethics of Undergraduate Student Participation in Short-Term Experiences in Global Health  
Nishita Pondugula, USA
  39. Ethical Issues of the Treatment of Chronic Pain in Older Persons: Use of Opioids  
Katarina Savić Vujović, Serbia
  40. Medical Ethics Questions in Serbia: Pain Management in Children  
Dragana Srebro, Serbia
  41. Medical Liability in Italy: One Year Analyses of Civil Court of Rome  
Michele Treglia, Italy
  42. Medical & Non-Medical Human Sex Selection in IVF: Ethical issues & Controversial Developments  
Marta Vaillant, Spain
  43. Health, Human Occupation and Justice  
Ana Luiza Zamai, Portugal
  44. The Constitutional and Legal Normative Force of the Brazilian Code of Medical Ethics  
Henrique Zarpellon Martin, Brazil
  45. Do young doctors know the "living will"? Cross-Sectional Study among Resident Doctors of the University Magna Graecia of Catanzaro  
Angelica Zibetti, Italy
  46. The Wish to Die in Stroke Survivors in Southeast Serbia  
Miroslava Živković, Serbia

## NOTES

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## NOTES

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# Abstracts Oral Presentations





## Challenges in Establishing an Effective Ethical Review System in Low - and Middle-Income Countries: Sudan as a Case Study

Shaza Abass<sup>1</sup>, Osman Osman<sup>2</sup>, Brair Sara Lavinia<sup>3</sup>

<sup>1</sup>University of Khartoum, Sudan

<sup>2</sup>Public Health Institute, Sudan

<sup>3</sup>Al Neelain University, Sudan

With the ongoing increase in human subjects' research in many low and middle-income countries (LMICs), there has been a strong urge to develop a robust ethical review system in these countries. In the midst of scarce resources and lack of infrastructure the national regulatory authorities in many LMICs are faced with challenges that hinder their role in regulating the ethical review process. These challenges include lack of governance, constitution and functionality as well as deficiencies in properly functioning research ethics committees (RECs). We are suggesting a framework for enhancing the ethical review capacity with emphasis on governance, coordination, feasibility, efficiency and sustainability. In Sudan, we had applied this framework through various activities that included reviewing the guidelines that govern human subjects research, enhancing the governance of national authorities, improving coordination between the national authorities by developing a consensus clarifying their roles and functions, capacity building for the oversight bodies and institutional ethical review committees (RECs) as well as establishing a network of research ethics committees. We believe that the array of activities conducted through this framework had enhanced the governance, coordination, feasibility and, efficiency of the ethical review system in Sudan.

## Human Rights for Medical Practitioners: Advanced Training in Human Rights and Ethical Principles in Clinical Settings

Mahmood Abdulameer<sup>1</sup>, Ana Paula Estrella Saa<sup>2</sup>

<sup>1</sup>International Federation of Medical Students' Associations, Iraq

<sup>2</sup>International Federation of Medical Students' Associations, Ecuador

The complex and intersectional nature of the world we live in, and especially health, is reflected in clinical settings. Hence human right education and medical ethics pedagogy is a necessary and essential part of medical education. With that in mind, the IFMSA developed a workshop, Human Rights for Medical Practitioners, dedicated to provide medical students with knowledge and skills to act according to Human Rights and ethics both in clinical settings and in everyday life. The workshop is based on a peer-to-peer approach and interactive exercises. Each workshop is themed to address the human rights and ethical perspectives pertaining to specific issues that can occur in clinical settings or otherwise have a strong relevance to the participants' future role as physicians. The methodology of the workshop serves its overall aim of increasing medical students' understanding of the intertwined nature of human rights and medical ethics, and to build capacity among students from a clinical perspective to apply a human rights-based approach into their medical practice. The workshop was first conducted in Stockholm in 2015 and has since been conducted 14 times in different regions of the world with a total of more than 200 medical students from all over the globe attending the workshop.

## Perceptions of Medical Students about Teaching and Learning of Medical Ethics and Professionalism

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Omdurman Islamic University, Sudan

**Background:** The issue of medical ethics and professionalism in medical curricula has been take a huge attention recently; because in a part is due to innovated curricula that constitutes with global changes in ethical issues and laws as well as emerges of new era of medical dilemmas.

The Faculty of Medicine and Health Sciences - Omdurman Islamic University (FoMHS-OIU), has two courses of medical ethics and professionalism in its curriculum.

The aims of this work; is to assess student's perceptions on medical ethics and professionalism course, and to determine its association comparing male and female students.

**Summary of Work:** A descriptive, cross-sectional institutional based study conducted among first-year medical students of FoMHS-OIU, 2018. It was total coverage, using modified Dundee Ready Education Environment Measure (DREEM) inventory questionnaire, the collected data was analyzed using (SPSS). The confidence interval is 95% was taken as significant at P-value  $\leq 0.05$ .

**Summary of Results:** There is no statically significant difference between male and female medical students regarding perceptions of teaching and learning of medical ethics and professionalism (P-value  $> 0.05$ ). Both male and female students revealed positive responds with high percentage.

**Conclusion:** The majority of participated students have achieved high scores in the perception of learning and teaching of medical ethics and professionalism in spite of their studying the course in the beginning of the college.

No gender difference in students' perception of learning medical ethics and professionalism.

## DNR Order: What are My Boundaries? Nurses Role and Attitude

Samah Abdulla Al Araiimi  
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Critical Care nurses are faced with multiple ethical and moral issues on daily basis. They deal with delicate, weak and terminally ill patients. They frequently need to take decisions which may sound harsh, tough and even nonhuman, such as explaining the Do-Not-Resuscitate (DNR) order to the patient, family member or the guardian. In addition, these decisions might have an undesirable impact on their care in End of Life (EOL) situations.

Despite the huge role they play, they are not usually involved in the decision making of a DNR order. Their intimate knowledge of the patients and the longer time they spend with their patients (compared to other health care providers) is usually neglected, while it should be taken in consideration while thinking of initiation the DNR Order. In addition, many people think that the DNR orders mean less care to their beloved ones, which puts another burden on the nurses to prove otherwise.

Although most of the health care institutions, globally, have a clear DNR policy, the role of the nurses is not well discussed, their attitude is not well studied and their role is not well defined. Many physicians have stated that the nurses could be of a great help when involved in such order. Also, studies should a positive attitude of nurses toward the initiation of DNR order for certain patients.

Nurses are the first line providers and their role in DNR initiation need to be formed, regulated and well established.

## Violence against Women in Health Services

Layla Abou El Hosn Cordero da Silva, José Antonio Cordero da Silva, Márcia Bitar Portella  
*Unifamaz - Centro Universitário Metropolitano da Amazônia, Brazil*

Violence against women in health services requires prior knowledge, so that professionals position themselves as facilitators of the therapeutic process, thus creating strategies with users, who respect and contemplate their social context and singularities. In a survey conducted by the Brazilian Institute of Geography and Statistics (IBGE) until the first half of 2016, 67,962 records of care were made at the Women's Care Center.

Among these reports, 51.06% corresponded to physical violence; 31.10%, psychological violence; 6.51%, moral violence; 4.86%, private prison; 4.30%, sexual violence; 1.93%, patrimonial violence; and 0.24%, human trafficking. Surveys show a higher prevalence of violence in women users of health services, a fact related to their complaints and seeking help, some professionals may have difficulty questioning the patient about a possible event for fear of offending her or not believing that Sexual violence is a health problem.

The curricular change in medical education proposes the humanized formation of these professionals, who would be able to understand and communicate properly with their patients, thus being able to provide integral, adequate and humanized care to women.

## Shared Decision-Making at End-of-Life Care for End-Stage Renal Disease Patients in Israel

Wassiem Abu Hatoum, Daniel Sperling  
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End-stage renal disease (ESRD) represents the final stage of chronic kidney disease (CKD). Some of the ESRD patients are deemed not suitable for dialysis while others become too frail. Decision-making concerning ESRD is often challenging for elderly patients, families and professionals, especially in cases of conservative care. Such care seeks to avoid poor quality of life, minimize pain and suffering, and reflects the view that it would be more 'natural' to die without dialysis. According to the Renal Physicians Association, shared decision-making (SDM), is the recognized preferred model for decision-making especially in ESRD patients requiring dialysis.

The proposed research examines to what extent nephrologist doctors and nurses pursue an SDM model while managing ethical dilemmas and clinical discretion pertaining to end-of-life care of ESRD patients in Israel. It has two purposes: 1) To measure the frequency, extent, characteristics and factors encouraging or inhibiting the use of SDM at end-of-life patients. 2) To explore the decisional conflicts, ethical dilemmas and sources of decision-making pertaining to these patients. The presentation will introduce and discuss the preliminary findings obtained through a questionnaire aimed at nephrology doctors and nurses and analyze the ethical implications of such findings to the clinic and physician-patient relationship.

## Creation of an Enabling Legal Environment to Ensure Rights to Access Healthcare in Nigeria

Oluwatemiloron Adenipekun  
*Wake Forest University, USA*

The Universal Declaration of Human Rights, 60 years ago, laid the foundations for the right to the highest attainable standard of health. Recognition that a strong health system is an essential element of a healthy and equitable society is growing. However, health systems in many countries are failing and collapsing. Too many health systems are inequitable, regressive, and unsafe. The World Health Organization confirms that sustainable development, depends on an effective health system. An effective health system is a core social institution and, for this reason, crucially, this system is protected by human rights. This paper proposes a legal reform in the current legal rights available in Nigeria to access healthcare. The law plays a key role in a country's progressive realization of Universal Health Coverage (UHC). The quality of a country's health law and legal practices significantly contributes to the efficient, effective and equitable use of the available health resources and, consequently the attainment of a country's health system goals. Therefore, creating an enabling legal environment for UHC is a critical investment to ensure the achievement of UHC policies and programs.

## Transplant Abuse in China and the Ethical Obligations of the Global Medical Institutions

Eddie Aitken  
*Spain*

Universities and medical institutions have research protocols and ethical standards that protect both human subjects, academics and medical staff, this paper investigates whether these same standards are applied regarding research collaborations with China, in relation to organ transplantation?

The China Tribunal, held in London in 2019, investigated forced organ harvesting from prisoners of conscience in China. One of the recommendations of the China Tribunal was directed at western medical institutions. This would relate to transplant medicine, research and training while raising a range of possible proactive measures that could be taken to ensure standards are upheld.

The presentation will also bring some of these findings to light in hope that the information will prove useful to the delegates in their respective countries in raising awareness of this matter and perhaps assist in bringing in new laws to protect their countries citizens from becoming complicit in this, similar to that in Spain, Israel and Taiwan.

## Informed Consent for an Emergency Procedure in a Mental Health Care User: A Case Report and Practical Applications

Andrie Alberts, Pieter Carstens  
*University of Pretoria, South Africa*

The theory and practical application of the doctrine of informed consent are separate entities in the domain of everyday clinical medicine. Often the theory of informed consent seems distant from the reality of everyday clinical practice. The practical application, on the other hand, finds itself wedged awkwardly into the heated clinical-practice/medical-law interface. Diverse reasons may explain this awkwardness but certainly includes the exposing of the delicate power vs respect balance in the doctor-patient relationship, ultimately pointing to the problematic quest for shared clinical decision-making. We use a case report to examine the ethical-legal underpinning of informed consent. We discuss the practical applications arising from the case report and suggest an approach to deal with similar clinical scenarios: Informed consent was required for an emergency procedure, the patient was a mental health care user, input from the Chief Executive Officer was requested, and extensions became necessary intra-operatively.

## Effective Rehabilitative Approach that Respects the Dignity of the Person in End-of-Life Care

Francesca Almonte Lalli, Laura Maria Castagna, Concettina Ruiz  
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Rehabilitation was born as a recovery of damaged functions, only in 1960 in England palliative care was born. The aim of palliative care is to control pain, other symptoms and psychological, social and spiritual problems.

Our rehabilitation department cares on average each year No 1500. of people No 150, in need of palliative care. These people in the absence of a Hospice, are hospitalized in various departments Stroke unit, Reanimation, General Medicine, Geriatrics.

The professionals (physiotherapists, nurses and speech therapists) twenty years ago undertook a training process to adapt their expertise to a situation of care completely different from rehabilitation as a functional recovery. In this change it was necessary to introduce the vision that the treatment aims to prolong and improve the quality of life to the end.

For this reason, physiotherapists have re-evaluated the role of manual contact, speech therapists have understood how the suspension of feeding by us, represents a mourning to be processed with the person and his entourage, the nurse has understood that hygiene but also the appearance of the body are essential to maintain the dignity of the human being.

The types of intervention we have adopted will be illustrated.

## Child's Rights under Surrogacy Arrangements

Marisa Almeida Araújo  
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The scientific development in Assisted Reproduction Technology (ART), especially through IVF (in vitro fertilization) solutions are promoting the development of our reproductive options that now have surpassed the traditional need for a heterosexual intercourse.

Surrogacy is nowadays one of these solutions and new ethical and legal problems arise. Domestic laws have the most different legal answers considering the ethical frontier zone in which surrogacy takes its place; the debate is even more exuberant since the concrete legal solution have a strong social impact and arises heated and controversial positions and International Surrogacy Arrangements (ISA) exacerbates this issue mainly considering State's international public order, promoting "IVF holidays" as an answer to achieve a parental project.

Surrogacy, as "new way of having a child" in a new "reprogenetic right" to achieve a parental project, arises ethical and legal issues that can have an impact in the child's to be personal integrity and identity, determination of parentage, civil status, the child's nationality and citizenship, the right to family life; besides commodification of the child, and a new form of positive eugenics, that lays at risk the foundation of human nature itself, and brings to the epicenter of the debate a new form of generational responsibility. The timeliness and importance of the subject requires us to focus our analysis considering the ethical and legal issues raised by the topic.

## Duel and Assisted Human Reproduction Techniques: The Psychoanalytic Clinic between Loss and New Life Construction

Diana Altavilla  
*Universidad del Salvador, Argentina*

If we agree, as Freud argues, that the duel begins only when there is a "loss record", we wonder how much and how the intervention devices of the Reproduction Centers favor or hinder this record and, in any case, what are the consequences of the absence of a loss mark.

If there is something nodal in the TRAS dilemma, it is that something is lost in the real. Something that is lost in some way. And that loss produces effects. If this loss is not inscribed in any way in the symbolic, another question will become in some form of a mark, for the mother, for both parents, for the son to come. The inscription of the Father's Name - or the substitute determinants of the same - will establish the way to access motherhood. If it is accessed without such registration, the child may be a mere object of the mother / father or of the medical-technological science, interposing to the same being constituted as a subject in a culture where it is included.

It will be essential to consider the fracture between the chronological time of the medical demand of the Assisted Reproduction Center and the necessary logical time (for the registration of the loss) of the subjects involved, where each subject can access the loss for someone by ad-come.

### Relationship Donors of Ovules and Clinics: Medical-Administrative Devices, Biomedical Practices and Sexual and Reproductive Health

Consuelo Álvarez Plaza, Maria Isabel Jociles Rubio  
*Universidad Complutense de Madrid, Spain*

The first Law 35/1988 on Assisted Reproduction Techniques facilitated the emergence of clinics, experts and pioneering knowledge that have made Spain an international reference in assisted reproduction treatments. The context of European globalization and integration and legislative diversity in the international environment have led to cross-border reproductive care and the free movement of people and goods that are affecting assisted reproduction techniques with reproductive donors. It is generating a flow of people and genetic material of Spaniards who go to countries where it is possible to satisfy their "reproductive desire" and foreigners who come to Spain for the quality of the clinics and for legislation that best suits their needs. This has impacted on the supply and demand of ovules in Spain.

There have been 38 interviews and 49 questionnaires for egg donors in four autonomous communities in Spain through four clinics (active donors) and through the "snowball" strategy (non-active donors). The results show those aspects that ovum donors themselves consider important for their health and social relationships before, during and after donation, as well as information about the process and the treatment received by biomedical professionals. This study is part of the project CSO2015-645 CSO2015-64551-C3-2-R, MINECO/FEDER

### Analysis of Gravidarum Eclampsia and Help Syndrome in Medical, Bioethics and Ethical Clinical Perspectives

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**Background:** Pre-eclampsia and eclampsia are the highest causes of maternal mortality in Indonesia. One of the risk factors for primigravida is 20 years old or 35. Immediate treatment is needed to save both mother and fetus.

**Observation:** A case report, female 46 years old, 34-weeks first gravida of pregnancy with eclampsia gravidarum and Hemolysis, Elevated Liver Enzyme, Low Platelet (HELLP Syndrome).

**Conclusion:** This case is a high-risk pregnancy, while the condition of the pregnancy is still premature. In the aspect of bioethics non-maleficence and beneficence, must be terminated immediately for the safety of the mother regardless of the condition of the fetus. From the autonomy, doctors have provided informed consent and the patient must make an immediate decision. An analysis was carried out with the APGAR family and the SCREEM method. This analysis is to see whether the family or sociocultural factors that influence patient decisions. In the perspective of clinical ethics of medical indication and quality of life are priorities, but consideration in patient preference and contextual features is a consideration in making this decision. The dynamics to this case required decision making in medical approach, bioethics and clinical ethics.

### Ethics Laboratory: An Important Applied Ethics Experience

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Roger Fernandes Campato,  
Lamartine Gaspar De Oliveira, Marcelo Silva Oliveira,  
Marcelo Martins Bueno  
*Mackenzie Presbyterian University, Brazil*

Contemporary society is characterized by the constant emergence of dilemmas of various orders, mainly of moral ethics, configuring challenges to be faced, problems not yet solved, obstacles caused by human action, whether in the natural or cultural environment. The impact caused by scientific and technological innovations is the subject of intense and continuous debate, both because of its potential to cause damage, as a consequence of social implications, and as a result of the transformations caused by intersubjective relations that take place publicly and in institutional spaces. The discussion becomes particularly fierce when considering the meaning and consequences of such advances in the face of the primary challenge of creating a society in which it is guaranteed by human rights and an integral dignity of individuals. Thus, the present work aims to present partial results of an ongoing Research Project that aims to initiate studies to verify the feasibility of implementing an Ethics Laboratory at Mackenzie Presbyterian University, São Paulo, Brazil, along the lines of the Ethics Laboratory (Kennedy Institute of Ethics - Georgetown University, Washington, DC). This first stage consisted of obtaining data from a visit at the laboratory site and holding an applied ethics workshop called *paideia*. The results show that the strategies developed at the Laboratory that addresses practical philosophy are an example of bioethics in action as an efficient education in values.

### The Dilemma of Pandemic Triage, Lessons for the Future: Comparative Frame of Ethical and Legal Issues in Italy, Germany and Israel

Teresa Andreani  
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The Sars-CoV-2 pandemic's outbreak has revived a never-ending question of modern bioethics: "tragic choices", how to allocate scarce life-saving treatments in case of disproportion between available resources and patients in need. Unpreparedly facing the exponential growth of hospitalization rate, front-line physicians initially adopted the criterion "first come, first served"; then, vastly confronting with the saturation of ICUs spots, they opted for "the patient affected by the severest health condition first". Consequently, a wide-spread debate on the adoption of ethically and legally legitimate criteria has transnationally surfaced. With the advent of vaccines, the controversy is currently paused but it is hardly a closed chapter. By pondering the dilemma in question in a comprehensive way, it will be firstly conceptualized and framed both in general terms and in detailed reference to the pandemic context. Secondly, the alternative ethical models and adoptable criteria of allocation will be theoretically proposed. Thirdly, the experiences of Italy, Germany and Israel will be concretely introduced as well as the contents of the relevant documents adopted and their peculiar and common traits. Ultimately, the legacy of this multidimensional discourse on triage will be considered as a valuable source of preparedness to face future public health crises.



## Legal Safeguards for the use of Health Data within the Public Health System in order to Improve Healthcare Quality

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The Spanish Public Health System owns a huge amount of information which not only is able to but also must be used for the improvement of the system itself, as well as of the quality of the healthcare. Taking the GDPR as a starting point, it is possible to use big data tools which allow, once anonymization and other safeguards have been carried out, to offer information for the improvement of clinic decision-making and those related to the health authorities. However, it is also relevant to determine in which particular cases and under which circumstances is it possible to use non anonymized health information. With the establishment of these type of projects the intervention of advisory committees acquires vital importance (a group of multidisciplinary experts in data protection and protection of others fundamental rights, ethics and cybersecurity) which outnumber the limited current frame of clinical research ethics committees.

## Person-Centered Health Care and the Patient's Fundamental Rights: The Right to Full Information and the Right to Patient Decision-Making Autonomy as Embodiments of the Principle of Human Dignity

Isa Filipa Ant3nio

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The idea that the healthcare professional can unilaterally decide on the best strategy for treating the patient by omitting clinical information or refusing to provide it is out of date. The "paternalistic relationship" that dictated the "doctor-patient relationship" of 20 years ago, in which the first expert in medical art and science, was that he decided on the patient's health, without listening to him in advance, without taking care of his opinion, fears and doubts is today contrary to good practice and law. The practice of the medical act in accordance with the law and legislation has dual legitimacy, that of the health professional and the patient. Full information on the actual state of health, the various treatment alternatives and the adverse effects associated with these therapies is imperative, so that you can make a clear decision about your life. The patient's consent, valid and in accordance with the law, must be freely given. The assumption of a person's "freedom of will" depends on the full clarification of all these aspects, assuming as corollaries of the principle of human dignity, the physical and psychic self-determination of the human being and the free development of the human personality. Any deviation from the right to information and consent limits the decision-making autonomy of the patient and constitutes a violation of those fundamental rights leading to the civil, criminal and disciplinary liability of the physician.

## Patient's Right to Hospital Responsibilities in Medical Dispute Resolution Reviewed from the Perspective of Vicarious Liability Theory

Wahyu Andrianto, Djarot Dimas Achmad Andaru

*University of Indonesia, Indonesia*

The imposition of legal liability upon hospitals in medical dispute cases in Indonesia has created differing perspective in defending patients right in medical dispute cases. based on an analysis of various court decisions using the Dworkin's theory of interpretation. It is found that the vicarious liability theory presents its own unique features when applied to hospitals' liability in Indonesia. The application of this theory becomes varied as it can become respondeat superior and ostensible agency. This polemic is reflected in article 46 of Law Number 44 of 2009 and number of court decisions on medical disputes. In view of the above, the present paper will be applying the Legal Theory of Interpretation to analyze the interpretations of legal principles by Indonesian judges in medical dispute cases.

## Strengthening the Other Side of the Table: Civil Society as a Prerequisite for Ethical Clinical Research

Kiarash Aramesh

*Edinboro University of Pennsylvania, USA*

The main concerns in the development of the leading theories of both civil society and clinical research ethics have been empowering the less powerful side of the table of negotiations and transactions. Having an organized and well-developed civil society is fundamental to protect and preserve the basic rights and freedoms of vulnerable social groups. In the same manner, having well-established research ethics instruments and institutions safeguards the rights, well-being, and interests of research subjects, and their families, communities, and countries, as the less powerful parties in the related negotiations and transactions.

This presentation argues that three necessary elements in effective research oversight cannot be achieved outside of civil society: independent professional institutions, independent oversight including IRBs, and room for the whistle-blowers.

This presentation discusses examples of developing countries that tried to establish research oversight, but they failed because of the absence of civil society infrastructures. They have been unable to establish independent IRBs. In addition, in the absence of independent social institutions such as professional bodies and advocacy groups, the only role-players are the authoritative governmental bodies that do not tolerate independent oversight or whistleblowing. Therefore, effective research oversight cannot be actualized in the absence of civil society.

## Small Animal Euthanasia from the View of the Private Practitioner and the Public Veterinarian

Yael Arbel  
Israel

According to the legislation in Israel an animal owner is obligated to care for its health, and specifically to provide in reasonable time, adequate treatment for its healing or relief of suffering. Moreover, in the event of animals suffering from malnutrition, obvious injury, or illness it is the owner's burden of proof that he has provided such treatment. Small animals' veterinarians often offer several diagnostic and treatment options according to the animal's condition, prognosis, and owner's economic constriction, compliance and beliefs. It is the private veterinarian's dilemma when to suggest the option of euthanasia, and when it will be the only option offered to the owner. In other conditions it will also be the private veterinarian's dilemma when to refuse an owner requesting euthanasia for an animal that doesn't require such measure. These dilemmas only multiply when it arrives to the public veterinarian. In the case of public veterinarians, public health considerations are added in some cases. In other cases, it is the public veterinarian's obligation to compel euthanasia, sometimes against the opinion of the owner and the private veterinarian. These dilemmas are unique to veterinarian medicine, and awareness to these issues is lacking to nonexistent during veterinarian degree studies.

## Participation of the People with Disabilities in Investigation Protocols

José Arias Porras  
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The investigation with human beings it's regulated by international organisms like the WHO, the guidelines of CIOMS, and declarations of human rights. The guidelines of CIOMS defines people with disabilities as a vulnerable population, that must be subject of empowerment to do enforce their rights to the system.

We need procedures of empowerment and an active participation in public politics, because the focus in protection could initiate an exclusion; or make the people with disabilities in passive subjects and deprive them to participate in the investigation field for a non-related disease with their condition.

The abuse can be present in situations like:

- a) Inclusion in clinical studies without their consent
- b) Exposed to unnecessary risks
- c) Rejection of compensation (or to a lesser extent compared to people without disability)
- d) Violate their confidentiality
- e) Exclusion of studies to avoid adjustments that makes the process more expensive

This Project had as overall objective verify if its known the reaching point of aspects like: vulnerability, investigation protocol, informed consent, and risk policies; then worked with members of this population to start a strategy of education and empowerment for the persons with disabilities with relation with their participation in scientific investigation.

## Ethics, Gender and Migration

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The basic problem of female emigration is not fully understanding what it means to address this issue from a gender perspective. According to the International Organization for Migration and for data collected from INEGI, it is estimated that by 2050 there will be 405 million migrants worldwide of whom 49% will be women. In the case of Mexico, it is estimated that in the January-September period were 20, 757 women (compared to 90,269 men) on the basis of data from women who crossed the country to US. Violence reported: in psychological abuse 49% men, 51% women, in physical violence both men and women were 16%, and in sexual assault, men 4% compared to women 45%. In short, women, poor, migrants lead to far less employment opportunities than men, greater dependence and exploitation by traffickers, a much greater vulnerability of sexual exploitation than men, restriction on basic services, and therefore increased risk of death. Conclusion: women's ethics requires to continue against those who accuse of gender ideology and therefore participate in the continuity of exploitation towards women, a struggle towards the establishment effective public policies for migrant women and finally towards opening critical discourse that makes visible the current migration phenomenon.

## Consulting "Dr. Google": How the Digital Search for Internet Health Information Influences Doctor-patient Relationship

Ricardo Arruda, Raymundo Azevedo, Maria Nunes  
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**Background:** The expansion of digital access has favored the use of internet by patients to search internet health information (IHI) in Brazil. This new behavior brought relevant transformations to doctor-patient communication and to medical practice.

**Objective:** 1) To determine overall patients' habits toward IHI and its impacts on doctor-patient relationship considering medical ethics  
2) To analyze behavioral differences in clusters of patients, for instance: age, having a child, gender, treating for common mental disorders

**Methods:** Validated questionnaires answered manually by 200 patients

**Results:** From 200 respondents, 87% declared to use internet; 74.5% search for IHI and 35% discuss IHI with doctors. Education level, age, gender and porting chronic diseases are the factors that mostly influent patients' behavior towards searching and discussing IHI with their doctors. Overall, patients desire more involvement in decisions concerning their health. Skeptical about IHI, they wish their doctors to inform them trustworthy sources of IHI. Short medical visit, discomfort in dialoguing and presenting information to doctors inhibit patients to approach those matters.

**Conclusion:** Despite broader access to health information, doctor-patient relationship remains well evaluated. Dissatisfactions reveal conflicts that should be analyzed in a constructive approach to improve medical relationship in this new technological and informational scenario.



## Assessment of Clinical Trials Localization in the U.S. and Africa as a Predictor of Global Health Disparities

Eric Asempah  
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When we consider the rate of preventable disease-causing mortality, and the minimal access and availability of essential medicine in Africa and other developing nations, there underlies a problem of geopolitical hegemony.

To delineate this problem, we looked at clinical trials localization and why investment in some low mortality diseases areas trump over high mortality ones in developing nations.

Datasets from ClinicalTrials.gov was mined for high mortality and prevalent diseases in Africa (Malaria, Tuberculosis and HIV/AIDS); and for those considered prevalent in the U.S. (Cancer, Heart Disease, Depression, and Dementia). A comparative assessment was made to elucidate and contextualize clinical trial localization as a marker for health disparity among regions of the world by the levels of access to essential medicine for preventable diseases.

The findings show that clinical trials completed in the U.S. for the disease areas under study mirror those completed worldwide. Thus, the more economically strong a country is, the greater it attracts or invests in more clinical trials. The assessment also shows that the priority clinical trial interest for disease in the U.S. drives how investment in Africa (developing nations) is shaped.

The trend delineates a structural process of health inequality which needs a focused and sustained drive for balance.

## The Contemporary Epistemological Sensibility with Social Ethical Demand: Approaches to African-style Bioethical Principles and Values

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In the view of social ethical demand, the contemporary epistemological sensibility is faced with a moral dilemma: How To rationally base the stakes and the challenges of ethical issues on the assertions of the quality of life without, on the one side, ostracizing the structures, the normative and institutional approaches but also on other, without risk of offending respect for the assertions of the rights, liberties and desires of individuals and societies.

Approaches to African - Style bioethical principles, norms and values.

## The Family Physician as Prophet? The Legal Implications of Fitness Certificates Issued by a Family Physician

Benny Avissar  
The Israeli Medical Association Ethics Bureau, Israel

The trust placed in physicians by the legislature, insurance companies and the public translate into various requests from family physicians to issue fitness certificates to their patients for a variety of activities.

Why is the physician entrusted with this request? Is it because we see in the physician a figure in whom society places their trust? Or is it because we rely on the physician's ability to confirm compatibility between the patient's physical state and the requirements of the activity?

In Israel, there are several laws requiring a physician's approval, such as issuing a license to bear arms, a driver's license, a pilot's license, employment of youth and others.

In February 2015, the Israeli Medical Association Ethics Bureau formulated ethical rules regarding fitness certificates issued by physicians and clarified the boundaries of the physician's professional ability to issue such certificates in different situations.

The legal system, too, must deal with the legal and ethical aspects of this issue. When is it legitimate and useful to rely on a physician's professional knowledge and skills essentially to predict the future, and when is it inappropriate to award him with the legal responsibility of doing so.

## Empathy Training and Bioethics in Clinical Settings

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**Introduction:** Experimental research suggests that empathy is an important predictor of the clinical ability of trainee doctors and patient outcomes. Empathy has been described as an important element of professionalism in medicine and the most commonly reported personality profile of the humanitarian doctor. Bioethics applies to a broad spectrum of issues within a clinical setting, from patient doctor confidentiality to palliative care. For clinicians it is important be aware of those issues and to know to follow the proper guidelines. "Empathy Skills in Clinical Settings Training" is a program of intensive experiential education on communication skills, patient understanding skills, conflict management and more generally mild skills, as well as which factors affect it especially designed for clinicians and medical students.

**Results:** Our preliminary data on 50 medical students (25 male 23 female 4th year and above) that took the course have shown a mean statistically significant rise of 11 points on the Jefferson Scale of Empathy after a 3-day course (t-test p0.001).

**Conclusion:** Intensive experiential training can improve empathy in a clinical setting, enhancing the ability of the clinicians to be aware of all the issues that require a proper bioethical approach.

## Education on Organ Donation and Transplantation: Ethical Dilemmas

Danica Avsec

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Slovenija-transplant as national competent authority, responsible for the education on organ donation and transplantation (ODT), must develop yearly educational plan. Education on ODT is carried out strategically in Slovenia. Before starting the education of medical students, we performed a short survey on their perception of ethical dilemmas in ODT.

Among sixty students of second class at Medical University in Maribor short questionnaire was distributed comprising 16 questions in the year 2019. The questions covered values, shortage of organs, quality of life after donation, brain death, principle of autonomy, allocation of organs, post-mortem interventions, risks in transplant medicine, life donation, informed-explicit consent, legislation and most topical current ethical issues.

We received forty-five (75%) fulfilled questionnaires. The results presented 85% of correct answers and demonstrated, students are informed about basic ethical and brain death aspects and general medical aspects on ODT.

We realized students were able to understand basic ethical dilemmas of specific field of medicine relatively comprehensively prior to education (they received training on brain death only). Based on preliminary results, Slovenija-transplant will develop advanced level of educational programme on ethical aspects in ODT.

## Cultural Competency and Skills for Nurses: Is it a Globalization Issue?

Pazit Azoury

*Tel Aviv Jaffa Academic College, Israel*

As a result of globalization and immigration processes around the world, states and societies encounter new challenges that they haven't met before; The new cultural mix that is made requires the different institutions to supply suitable services for the diverse ethnic groups (Asgary, 2013).

Cultural competence is the set of behaviors, attitudes, and policies that work effectively in cross-cultural situations. It is affected by the immediate financial, political, social, historical, and cultural context. Cultural-competence development is a dynamic and evolutionary process, which necessitates personal desire and effort, effective education, and organizational support. It gives nurses a sense of self-empowerment, provides patients a sense of cultural safety, and improves community health outcomes. (N. Sharifi et al, 2019).

Developing cultural competence in health services requires a sustained focus on knowledge, awareness, behavior, skills and attitudes.

The aim of the study is to determine the best combination of strategies to improve cultural competence for nurses. Nurses from four countries ISR, AUS, CYP, UK, completed questionnaire Inventory for Assessing the Process of Cultural Competency (IAPCC, Campinha-Bacote, 2009). The results showed the differences attitude to cultural competency and helped to create a cultural competence intervention for nurses.

## Animal and Science: An Incomprehension Story

Virtudes Azpitarte

*Valencia University, Spain*

Scientific methodology it's one of the cultural reasons of animal's situation today. Reason's supremacy, logic, mathematics, physics, they all blind animal's comprehension. We try to quantify their intelligence as a scale of life. From an intended objectivity, anthropocentric and unique, we forge criteria and results. Rationality is the big tyrant to animals' world, and it has justified man's domain and exploitation over the whole nature.

Lab animals, and those of intensive breeding farming, are the exponent of this unfair situation. Regretfully, though visibility and complaint voices increase, tech era has exponentially raised the problem. Pandemic new era has intensified it to the maximum.

The question about the man is also the questions about the animal, the one we are and the one we live with. Animalism is the new humanism.

Animal exploitation must not be afforded from compassion or benevolence. It's a matter of justice: animal's rights as the last frontier to conquer in the fight for justice, for human rights.

## Artificial Reproductive Technology for all Women and Equality: A Question of Right or of Justice? Analysis of the French Context

Maroun Badr

*Ateneo Pontificio Regina Apostolorum, Italy*

The new bioethics law project in France, proposed in 2019 and approved by the National Assembly on June 29, 2021, makes in its first article, concerning the ART (Artificial Reproductive Technology), modifications to article L. 2141-2 and L.2141-3 of Law 2004/2011. It thus gives the possibility to "any couple made up of a man or a woman or of two women or any unmarried woman" for easy access to ART, by deleting the medical criterion of sterility / infertility. Is ART for all women a right? Is it legitimate to claim it in the name of equality? What about justice? In this presentation I would like to approach the subject from a bio-legal point of view by situating the problem within the framework of the philosophy of law.

## Bioethical and Legal Challenges of Legal Personality

Stela Barbas<sup>1,2</sup>

<sup>1</sup>University of Porto, Portugal

<sup>2</sup>Universidade Autónoma de Lisboa, Portugal

- Introduction
- Legal personality
- Personality rights
- Law and Bioethics
- Neuroethics and Law
- The human being as object of the legal relationship?
- Medically assisted procreation
- Living Wills
- Law and the human genome
- Predictive medicine and gene therapy
- Palliative care
- The right to personal and genetic identity
- Equality versus discrimination
- Legal framework
- Autonomy of the will versus determinism
- Human dignity and human rights
- Conclusion

## Amazonian Indians: A New Genesis for Humanity? A Discussion of the Idea of Vulnerability Applied to Indigenous Minorities

Braulia Ines Barbosa Ribeiro

University of St. Andrews, UK

Recognizing and respecting the “otherness” of ethnic groups is considered to be a moral responsibility of any host nation-state. In Brazil, the language used in such ethnic-minorities public policies is carefully chosen to reflect an ideological stand that unfortunately has tragic practical consequences. I investigate in this paper the influence of the metaphorical language that frames the discourse of the legislation concerning indigenous minorities construed in Brazil and how its application has been proven to be problematic. This paper deals with the ethical limits of the use of the notion of alterity in the domain of public policy. I will examine two case studies to point to how the notion of extreme alterity is a setup for injustice. The first is the case of the Zoë tribe that live trapped in a well-designed human zoo. The other is the case of the “Man of the Hole” last survivor of his tribe, who lives alone for two decades under the surveillance of the government that forbids his contact with any other human being, under the pretense of cultural protection. I argue that we have to postulate an ethical limit to the collective culture’s authority over the individual’s well-being, or we will inevitably incur in the fatal mistake of using these tribes as buffers of Western guilt, sacrificing real human beings for the sake of abstract Western concepts that only exist in the imagination of anthropologists.

## Distinguishing Between Moral Injury and PTSD

Terry Bard

Harvard Medical School, USA

The recent COVID-19 pandemic generated medical, social, economic, psychological, and spiritual challenges worldwide. Even post vaccines, its impact will continue to affect all aspects of life globally. The anxiety and stress generated is unlikely to dissolve now that people have been vaccinated. Care providers, victims, and their families may experience long-term effects that challenge daily life. Many are likely to experience symptoms of PTSD and Moral Injury. Distinguishing between these two reactions deserves attention. Recognition of these distinctions provides opportunities for differential treatment. Ethical dimensions inhere in each reaction, and clinical and ethical treatments become central in helping others in their responses to what they have experienced during this pandemic as well as in similar life-situations that generate PTSD and Moral Injury.

## Dealing with Ethical Challenges in Qualitative Research: An Epistemologically Consistent Proposal

Maria Luz Bascunan

Universidad de Chile, Chile

The aim of this piece of work is to describe the main ethical challenges of qualitative research and to propose an epistemologically consistent way of dealing with them.

We know that research ethics has been focused from the beginning on biomedical studies within a positivist paradigm, so that qualitative researchers (including multiple perspectives) have faced a regulatory framework that tends to ignore their epistemological discourse and research methodologies.

Considering the popular requirements described by E. Emanuel (1999) and other criteria; we summarize five aspects that seem especially complex in the ethical analysis of qualitative studies: 1. Qualitative research is a living- open process; 2. Qualitative research questions the classic quality criteria of validity and reliability; 3. Qualitative research is especially appropriate for studying vulnerable groups and sensitive issues; 4. The researcher is an active participant and the relationship between researcher and participant is close; and 5. Qualitative research is situated and contextual.

Each of these assertions is analyzed from an epistemological point of view in order to present a ethically grounded proposal is presented in order of facilitate the work of researchers and members of the Institutional Review Boards.

## The Dilemma of Property Law in the Context of Human Body in the Science of Medicine

Jerzy Bednarski<sup>1</sup>, Weronika Wojturska<sup>2</sup>,  
Iwona Łuszczewska-Sierakowska<sup>1</sup>, Jacek Baj<sup>1</sup>, Agata Nogalska<sup>1</sup>

<sup>1</sup>Medical University of Lublin, Poland

<sup>2</sup>University of Warsaw, Poland

The presentation aims to set out the authors' comprehensive legal analysis of the concept of consent for medical and educational usage of human body and its parts by referring to Polish case-law, medical guidelines and ethical perspective.

On the one hand, the wording of the Convention on Biomedicine speaks for the importance of the subject, which among the basic principles of medical law includes a ban on commercialization of the human body and its parts, as well as the activity of the Community legislator, which emphasizes its attachment to the principle of non-commercialization of the human body. On the other hand, the significance of the problem is convinced by the fact that despite the declared attachment to the principle of non-commercialization of the human body, there are various theories and definitions regarding the body, its products and services that require more extensive analysis. Therefore, one can admit that the problem deserves to be taken up in the bioethical debate.

In the absence of codified regulations, the authors clarify the premises for defining detailed legal definitions and creating law which will allow beneficial use of corpses, which will contribute to the development of medical training and proper handling of the corpse.

## Coercion and Freedom

Jeffrey Bedrick  
Christiana Care, USA

Can coercion and cooperation coexist? Not in the case where the patient has an advance directive saying what to do should they become psychotic, but in the case where at the time you are being coerced you are absolutely not doing what the patient expresses to be wishing (even if afterwards they thank you)? And what if after they say you should not have intervened—even if it was the intervention that is allowing there to be a conversation “after”? What would ever allow us to say that we knew what the patient wanted more than they did? It is not so uncommon for someone to say that “You know me better than I know myself” –and perhaps this is even more likely in non-therapeutic settings. I argue that a conception of mental disorder as a disorder of freedom can help us determine when coercive methods can be ethically grounded. I discuss the idea that coercion can be justified when it leads to an increase in freedom, as utilitarian might, or as Merleau-Ponty did on different grounds in Humanism and Terror, and the shortcomings of such an account: How much impairment in freedom must exist before this is justified? Is it, for example, justified in the absence of any impairment of freedom? A close analysis of the disorders of freedom that constitute psychiatric disorders, which is outlined in the paper, proves useful in answering these questions and helping us determine when a person's freedom is so impaired that external coercion can be justified.

## Holocaust Bioethics Education: Setting the Context and the Relevance

Ira Bedzow  
New York Medical College, USA

Medical Education is intended to impart necessary biomedical knowledge and clinical skills on students so that they can perform entrustable professional activities (EPA), which are tasks or responsibilities that can be entrusted to a trainee once sufficient, specific competence is reached to allow for unsupervised execution. Therefore, when medical schools introduce humanities curricula, which includes bioethics and history of the medical profession, those components must be seen as integral to adopting or refining clinical skills for them to be relevant to students' medical education. As such, for Holocaust Bioethics to be successfully incorporated into medical school curriculum, it is not enough to justify its introduction because of its general or over-arching importance. It must lead to the development of particular and practical skills. Understanding this context could allow educators to create curricula that can introduce Holocaust Bioethics that is deemed relevant. In this lecture, I will lay out how a Holocaust Bioethics curriculum can facilitate students' achievement of specific milestones and competencies in their medical training. In doing so, I will demonstrate the relevance of Holocaust Bioethics to Core Competencies in Medical Education.

## Reasons and Un-Moderating Sources for HPV Vaccination Hesitancy among Ultra-Orthodox Jewish Mothers

Miriam Bentwich  
Bar-Ilan University, Israel

**Background:** Vaccination against the Human Papillomavirus (HPV) is a pivotal tool for preventing cervical cancer. A known decreased willingness to consent to this vaccination is associated with religious parents. However, there is scarcity of studies focused specifically on non-Christian closed religious groups.

**Purpose:** To understand better the basis for the negative attitude to the HPV vaccine in a Jewish ultra-orthodox religious community, and how it can and cannot be reduced.

**Methods:** Qualitative study, based on semi-structured interviews conducted with ten Israeli ultra-orthodox women that are opposed to administering the HPV vaccine to their daughters.

**Results:** we found four main novel insights concerning the negative stance toward HPV vaccination. (a) Lack of knowledge about HPV vaccine is not part of the reasoning against it. (b) Rabbinical authority might have a lesser influence than expected regarding HPV vaccination hesitancy. (c) Complicated viewpoints regarding childhood vaccination may be the larger context for HPV vaccination hesitancy. (d) Importance of cultural competence for changing the negative attitude to HPV vaccination.

**Conclusions:** This study highlights the importance of reaching a better understanding of the reasons for opposing the HPV vaccine in an Ultra-Orthodox community and finding population-oriented ways to deal with such opposition.

## Non-Medical Factors Associated with Postponing Elective Operations

Sven Bercker, Julia Becker, Petzold Hannes-Caspar, Huschak Gerald  
*University Hospital of Leipzig, Germany*

In acute care hospitals shifting of elective surgery is often unavoidable. In this study we analyzed the association of non-medical risk factors with the risk of postponing elective surgery.

Within 7 months all adult patients in the anesthesia walk-in-clinic who were scheduled for elective surgery in 5 medical departments of the Leipzig University Hospital were asked to answer a questionnaire and to participate in this study. Postponed cases were compared to those conducted as planned using the chi-square test.

2589 surgical procedures were included, of which 167 (6.45%) were not conducted as planned. There was an association with increased age (65y), retirement, nursing home residents, type of health insurance and colonization with multi-drug-resistant pathogens and postponing surgery. No association was seen with non-German or non-EU origin and postponing.

We demonstrated that patients with certain risk factors were more prone to be postponed in elective surgery. We hypothesize that this had no purely medical reasons and could at least be partly explained by a lower psychological threshold to offer such patients shifting of an elective procedure. However, special attention should be paid to avoid such effects which have the potential to undertreat underprivileged patients.

## Bioethical Aspects of the End of the Life and Judicialization of Health in Brazil

Mirella Rebello Bezerra, Laiane Dias, Maria Julia Mello, Jurema Telles  
*Instituto de Medicina Integral Prof. Fernando Figueira, Brazil*

The judicialization of health is a current phenomenon that has been raising important questions about individual and social rights. Accessing treatments necessary to maintain quality life can make sense and be positive for both the individual and society. However, in the end of life, judicialization can give access to treatments that do not respect the bioethical principles leading the individual to unnecessary suffering. CFM's Orthothanasia Resolutions and Advance Willing Guidelines aim to protect people from therapeutic obstinacy but are not always used by physicians.

This review aimed to build a rationale that is based on the bioethical aspects of the end life as protectors of the right to "dignity of the human person" can minimize unnecessarily judicialization of health resources. The literature review was performed in Medline, Scopus and BVSsalud, using the Meshes: "judicialization of health", "bioethics" and "terminality of life" and synonyms.

Some studies were found that corroborate the objective of this paper. However, it is necessary to broaden the discussion.

## Blaming Genes and Ignoring Structures: Covid-19, Down Syndrome, and Social Determinants

Sara Bergstresser  
*Columbia University, USA*

As the Covid-19 pandemic spread, a realization emerged that people with Down Syndrome (DS) were at higher risk both to develop Covid-19, to have severe illness, and to die of the disease. Initiatives to study this phenomenon and to advocate for preferential vaccine eligibility followed, with a focus on identifying biological pathways and genetic risk factors. During that period, in the US it also became clear that individuals living in nursing homes were at very high risk, but clusters at disability-related residential institutions remained largely ignored. Since then, researchers continue to seek genetic and biological explanations for associations between DS and Covid-19, but in the US few attempts have been made to rethink existing institutional systems for individuals with disabilities.

This paper frames the issue in terms of bioethics, disability studies, and human rights. It addresses the ways in which biological reductionism and medicalization continue to be used to conceal or deny systemic inequality for individuals with DS and other intellectual, developmental, and psychiatric disabilities. Inequality is routinely normalized based on presumed or hypothetical biological differences while social and structural constraints are dismissed or ignored. Awareness of social determinants of disease must become intrinsic to the bioethical concept of Justice.

## Gender Identity vs Legal Sex. Limitations in Access to Health Services: Polish and German Perspective

Agnieszka Bielska-Brodziak<sup>1</sup>, Martyna Łaszewska-Hellriegel<sup>2</sup>

<sup>1</sup>University of Silesia in Katowice, Poland

<sup>2</sup>University of Zielona Gora, Poland

In most of countries, a very strong identification with the binary division of the world may be observed. In effect, strong identification with official way of assessing legal sex, as well as strong need to defend what has already been defined and established as male or female is noticed. Our considerations are based on the distinction between gender identity and legal sex. Although these notions seem to be coherent, they may be conflicted for some minority members. We will discuss transsexual and intersexual person cases.

Limitations in access to health services may be either connected with medical sex correction or separate from that process. They may concern both adult and underage patients. These limitations are effects of many factors. There are not only shortfalls of the legal system, but also other relevant factors, such a lack of social awareness or willingness to accept differences (as a consequence of religious and cultural background). Last two aspects strongly affect directly the legal system and produce socially accepted interpretations of law.

Combining of Polish and German perspective will show us just how greatly are we able to sacrifice the good of non-binary people in order to defend our traditional binary mindset.



## Bioethics Education: Developing a Bioethics, Law, and Literature Curriculum as a Means to Teach Cultural and Racial Sensitivity

Barbara Pfeffer Billauer<sup>1,2,3</sup>

<sup>1</sup>University of Porto, Portugal

<sup>2</sup>Institute of World Politics, USA

<sup>3</sup>Israel

This proposed course incorporates literature to enlarge appreciation of bioethical dilemmas and long-term consequences of current legal and bioethical resolutions. The curriculum especially aims to promote sensitivity training to cultural and racial diversity.

By way of example "dignity" and respect for cultural beliefs are often invaded when a Jehovah's Witness child requires a life-saving blood transfusion. Courts routinely remove parental custody under the aegis of *parens patriae*. Assessing long-range impact of that decision is not the purview of courts nor the bioethicist, and late-developing ramifications may prove problematic. These consequences are difficult to even imagine, other than in real-life cases - or literature. The Children Act, by Ian McGewan, poignantly illustrates such consequences - setting forth a pedagogical landscape to probe current decision-making paradigms. Another example addresses autonomy. Do we consider whether external circumstances might disempower persons - such they do not feel they have autonomy? Octavia Butler's story, *Kindred*, demonstrates the impact of political climates on people who, while legally autonomous, are situationally denied freedom of choice, such as when a nurse thrusts a DNR order in front of a patient, demanding a signature. Allowing students to imagine such situations via a story may serve as our best pedagogical tool.

## The Covert Costs of Racial/Ethnic Concordance in the Medical Workforce

Elizabeth Bogdan-Lovis<sup>1</sup>, Karen Kelly-Blake<sup>1</sup>, Nanibaa' Garrison<sup>2</sup>, Faith Fletcher<sup>3</sup>, Brittany Ajegba<sup>1</sup>, Nichole Smith<sup>4</sup>, Morgann Brafford<sup>5</sup>

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The face of the United States medical workforce has shifted to become more fully reflective of the nation's diversity. There has been a 'widening capacity' trend toward enhancing ethnic, racial and linguistic population representation, commonly linked to notions of desirable doctor/patient dyadic concordance. Notably that trend is accompanied by rhetoric covertly shaping the professional lives of Native American, African American, and Latino physicians underrepresented in medicine (URiM). Improving patient trust, access and health outcomes are frequently mentioned benefits figuring into such parity rhetoric. Indeed, URiM physicians provide a substantial proportion of medical care to the underserved. Quite possibly such workforce patterns reflect focused altruism to serve 'one's own.' Paradoxically, policy initiatives that influence URiM's futures in the medical workforce may well carry hidden unanticipated consequences.

Recognizing the critical distance between policy and practice, we conducted a 2000-2015 scoping literature review. In our analysis we consider the nature of medical workforce policy strategies. We ask if those strategies might not unevenly affect URiM physicians, selectively placing service expectations not similarly placed on their non-minority physician colleagues. We examine the literature to see how URiM physicians might be disproportionately tasked with ameliorating persistent inequities in our health care system.

## Medical Students in Emergency Response: Between Obligations and Safety

Iris Martine Blom<sup>1</sup>, Mahmood Abdulameer<sup>2</sup>, Anastasia Martin<sup>3</sup>, Maria Inês Francisco Viva<sup>4</sup>, Gemma Whyatt<sup>5</sup>, Karan Sanjay Parikh<sup>6</sup>, Alaa Abusufian E. Dafallah<sup>7</sup>

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Health systems have been overburdened worldwide as a result of the COVID-19 pandemic, exposing and aggravating a shortage of resources in healthcare. In order to support the health workforce, medical students took on a variety of different roles. They are a unique population that has knowledge and skills to contribute meaningfully towards the provision of healthcare and the promotion of health. However, their roles differed greatly across the globe. The aim of this study is to shed light on the role of medical students, including ethical and safety considerations.

A global quantitative study was held in April to assess the roles of medical students including their perception, which received responses from 101 countries. The results will be presented and reflected on in the context of infrastructure, countries' preparedness, but also culture and politics. Safety and duties of medical students during health emergencies, the wellbeing and rights of medical students, and the value and ethical dilemma of education during health emergencies will be discussed. Participants will be encouraged to further reflect and engage in follow-up discussions post-presentation the involvement of students in the COVID-19 response and the possible ways of safeguarding the human rights of students in current and future emergencies.

## Physicians' Perspectives on Ethical Issues Regarding Access to Expensive Cancer Treatments: An Interview Study

Charlotte Bomhof, Eline Bunnik

Erasmus Medical Center, The Netherlands

**Background:** When cancer treatments have been given market authorization, but are not (yet) reimbursed within a healthcare system, physicians are confronted with ethical dilemmas: arranging access through other channels, e.g. hospital budgets or out-of-pocket-payments by patients, may benefit patients, but leads to unequal access. Until now, little is known about the perspectives of physicians on access to non-reimbursed treatments. This interview study maps the experiences and moral views of Dutch oncologists and hematologists.

**Methods:** A diverse sample of oncologists and hematologists (n=22) were interviewed. Interviews were analyzed thematically using Nvivo 12 qualitative data software.

**Results:** This study reveals stark differences between physicians' experiences and moral views on access to cancer treatments that are not (yet) reimbursed: some physicians try to arrange other ways of access and some physicians do not. Some physicians inform patients about cancer treatments that are not yet reimbursed, while others wait for reimbursement. Some physicians have principled moral objections to out-of-pocket payment, while others do not.

**Conclusion:** Oncologists and hematologists in the Netherlands differ greatly in their perspectives on access to expensive cancer treatments that are not (yet) reimbursed. As a result, they may act differently when confronted with dilemmas in the consultation room.

## Informed Consent and Artificial Intelligence: An Incompatible Pair?

Christopher Boniface  
University of Canterbury, New Zealand

As new technologies and methods in medicine emerge, established legal doctrines and rights must be re-evaluated to determine if they need revision, or an overhaul, considering these developments. Artificial Intelligence (AI) represents a potential paradigm shift in the provision and improvement of healthcare and is accompanied by a potential wave of legal conflicts and new questions that must be addressed.

The use of aggregated data and deep learning networks present new problems for the staple principle of informed consent. Once data is collected by a system – often-times beyond the data's original jurisdiction – control of this data can be lost, or even misunderstood by both patient and healthcare provider resulting in an uncertainty as to the information's future. Not only can this data continue to be used beyond its original purpose as a seemingly anonymous data-point amongst a wider set, but it can also be used for an AI to reach conclusions that a patient might not want to know.

This paper will discuss a few select scenarios and problems presented by AI technologies in respect of informed consent, and where the law might have to go to adapt to this modern world.

## Human Germline Gene Editing: Did Jiankui He's Experiment Open Pandora's Box? Critical Issues and Future Perspectives

Sara Bonomelli  
State University of Milan, Italy

The perspective of intentional changes in human germline has represented both a source of fascination and bewilderment for decades, mainly because such modifications would be inherited by next generations. Even - but not only – in the light of its transgenerational repercussions, germline gene editing has always raised numerous bioethical, philosophical, scientific and legal issues. Until recently, the very few experiments carried out in this field hadn't pursued a reproductive goal, as the scientific community agreed on the fact that the technique is still in its infancy, and any clinical application would have been definitely premature. However, in 2018, Chinese researcher Jiankui He announced to have helped making the world's first genome-edited babies by an experiment which seems to have changed the nature of the debate on this controversial application of genetic engineering, turning germline gene editing from a speculative reality into a practical and concrete one. The aim of my presentation is to identify the main ethical, legal and scientific criticalities raised by Jiankui He's case and to develop some reflections on the possible, future perspectives related to the therapeutic use of germline gene editing techniques, paying particular attention to the issue of the role of bioethics in their governance.

## "None but Ourselves Can Free Our Minds"(?): The Contribution of Hospitals' Practices to the Responsible Development of Commercial Brain-computer Interfaces

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Informational superpowers, such as states and several private companies, develop and provide a wide range of brain-computer interfaces (BCIs) to their citizens/users, to be used for commercial purposes. Such tools evoke legal ambiguities concerning the permissibility and extent of use thereof as BCIs interfere with certain fundamental rights in connection with the human mind.

Based on the European Convention on Human Rights and the existing jurisprudence of the European Court of Human Rights it can be inferred that interference with the mind by BCIs are permissible but only until a certain extent. However, in psychiatric hospitals interference with the mind of the patients with serious psychiatric disorder or mental health problem seemingly surpass these legal limitations as patients' minds are interfered with for the aim of 'correction' and treatment.

This contribution aims to elaborate on the extent and nature of interference with as well as the perception of the mind by clinical psychologists and clinical psychiatrists. Mapping and elaborating on the everyday practices of the interference with the mind, compared with the abstract legal reasonings will assist developers concerning the legal and ethical boundaries of developing and providing brain-computer interfaces for commercial purposes.

## The Doctor Who Swims Against the Current: The Legal Approach

Malke Borow  
Division of Law and Policy, Israeli Medical Association, Israel

A physician who swims against the current by espousing an unpopular viewpoint clearly raises ethical issues but may raise legal ones as well. The Israeli Patients' Rights Act directs that, for purposes of informed consent, a physician must detail various treatment options available to the patient. How far does this extend to alternative, unproven treatment? To those steeped in some controversy?

Medicine is not comprised of incontrovertible truths. Doctors may disagree on a wide variety of matters. In Israel, informed consent is judged by a "reasonable patient" standard, rather than the mostly defunct Bolam "reasonable physician" test. Therefore, one could argue that even treatments not in the consensus should be at least mentioned, especially when the patient indicates a desire to be informed or a bias towards a specific treatment.

On the other hand, might a doctor who does so be sued for negligence if the patient later suffers damage and claims he or she did not realize just how medically unpopular the option was? Can the medical community even sanction the espousal of unpopular viewpoints? These are all questions that must be explored from both a legal and an ethical standpoint.



### **Moral Friendship as the Cultivation of Moral Taste and Judgment in Professional Life**

Jon Borowicz  
*Milwaukee School of Engineering, USA*

Some of the most infamous instances in the historical case canon of professional ethics were results of failures of judgment not in the sense of their being exercises of poor judgment, but as instances of having failed to judge at all. Hannah Arendt's argument that the great evils of the 20th century were the results not of "wickedness," but of thoughtlessness—the failure to think—made with respect to mass society's response to totalitarianism, is more compellingly made in consideration of the repression of professional judgment by the organizational circumstances of the bureaucratic professions.

The paper will describe a pilot program of moral friendship in professional life realized on the asynchronous collaboration platform, Twist, designed to resist thoughtlessness through the cultivation of moral taste and judgment. Introduced to students in their professional education, the activity is designed to be sustained in their professional lives as supported by their universities. Realized on a broad scale among networks of collaborating universities, the philosophic-ethical practice of moral friendship described would address a lacuna in professional ethics education which typically presumes that ethical issues are readily apparent and well-behaved. The paper will conclude with an invitation and call for collaboration.

### **Dignity at the End of Life: What Can the Law Do to Achieve that Goal**

Patrizia Borsellino  
*University of Studies of Milano-Bicocca, Italy*

In the last decades, end-of life has become a crucial topic in philosophical-legal and bioethical research, which has focused and still does on questions regarding meaning of dying with dignity and conditions, to be granted to all individuals, for ending life in a dignified way. The debate has however highlighted relevant disagreements with regard to the notion of 'dignity of dying'.

The analysis realized in the presentation will argue in favor of the thesis that dying with dignity requires first of all that the suffering patient is never subject to others' interests, including family, who often wants to prolong life at any cost. In the second place, it requires that we really understand how devastating is the impact of lies on the patient's overall condition. Finally, it requires that efforts be made to overcome prejudices in order to preserve the patient from mortification caused by not been considered any longer a person with full rights: This occurs anytime the patient is denied the right to choose and possibly adopt nonconformist lifestyles. Conclusions of the paper focus on some considerations concerning values at stake and foreseeable impacts on health policies and legal regulations regarding the vision of dying with dignity in the shape of the proposed definition.

### **The Right to Conscientious Objection in Medicine and Political Disobedience in Kant and Rawls**

Georgios Boutlas  
*National and Kapodistrian University of Athens (NKUA), Greece*

The right to conscientious objection in medicine remains an object of heated bioethical debate. The wide diversion of opinions on that matter mirrors the moral controversy among health care professionals as also the public. The 'Swedish solution' does not recognize any legal right to conscientious refusal on any ground (moral or religious) while medical organizations worldwide express their strong opposition. Bioethicists like Julian Savulescu and Udo Schuklenk argue that "there should be better protections for patients from doctors' personal values" and doctors with conscience issues should 'go home'. Others like Christopher Cowley claim "that the health service should expend more to protect conscientious objection" while ensuring universal access to legalized practices. Both sides use a slippery slope argument, one side's slope leading to the generalized prohibition of any conscientious objection even on highly controversial issues like euthanasia and abortion and the other sides to the right to object even in trivial and generally accepted practices. Is there a moral duty to obey the law or must we adopt political disobedience on moral grounds? We will try to elucidate the discussion on that problem by Immanuel Kant's and John Rawls' opinions, the former addressing at the right of revolution and the latter at the equal liberty of conscience.

### **Poachers and gamekeepers? Misunderstandings between the Pharma Industry and Medical Ethics Committees**

Sara Branders  
*Medical Ethics Committee, University Hospital Brussels, Belgium*

A look behind the scenes, experiences in ethics review procedures for clinical research from both sides: the pharmaceutical industry and the medical ethics committee.

Many misunderstandings between industry and Ethics Committees exist. Does the pharmaceutical industry look for loopholes with only one goal: to start their trial as soon as possible? Does 'ethics shopping' exist trying to avoid the most strict and 'difficult' committees. Don't all ethics committees work the same way? Do some committees work slow while not having a lot of work, hampering innovative research? Is the ethics review too extensive and unreasonable for all industry submitted trials? These are some of the (mis)conceptions that live in the clinical research review environment.

Some thoughts and clarifications from a poacher that became gamekeeper...

## Bioethics and the Holocaust: Results of an Experiential Learning Pilot Program for Medical Students and Trainees in Poland

Rebecca Brendel  
Harvard Medical School, USA

The legacy of physician participation in the Nazi program of eugenics and genocide has served as a critical influence in contemporary bioethics and has influenced approaches to current medical and biotechnological advances from genetics and public health initiatives to beginning and end-of-life care considerations. In this presentation, we describe the experience of developing and implementing a pilot scholarship-supported one-week experiential program based in Krakow, Poland for students and physicians-in-training to learn about the role of Nazi medicine in the Holocaust and the implications for medicine today and in the future. We report the preliminary lessons from and results of the program, which is centered around the third annual Medical Review Auschwitz: Medicine Behind the Barbed Wire (MRA) conference (2020). The key elements of this program for students and trainees include pre-conference introductory learning, an experiential learning component in Poland including exploration of key sites providing context for the rise of Nazism and the location of concentration camps surrounding Krakow, a visit to the Auschwitz-Birkenau complex with a focus on areas of relevance for Nazi medicine, attendance at the MRA conference, participation in small group reflection and debriefing sessions to assess personal and professional lessons, and post-trip follow-up. Lessons from this pilot program and directions for future learning will conclude the presentation.

## The Intensive Care as an Epistemic System: Invisibilities, Epistemic Injustice and Testimony

Renata Breves<sup>1</sup>, Luciana Garbayo<sup>2</sup>  
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<sup>2</sup>University of Central Florida, USA

This study investigates the emergence of the intensive care as a normative space, through the lens of social epistemology and clinical bioethics. It discusses the systemic social epistemic history of medical knowledge in the intensive care space, considering the role of the knowledge of nursing and of patients in decision making. First, an analysis of the construction of the intensive care space as an epistemic system is provided, historically limited by its emergency conditions and its epistemic social reproduction; secondly, an ethical analysis of the intensive care space and its epistemic limitations is suggested, pointing out instances of epistemic injustice in its interface with ethical violations to the principles of autonomy, beneficence, non-maleficence and justice in the context of patient-centered care. Recommendations are suggested for the ethical-epistemic amelioration of health practices organization in the intensive care space, especially, regarding the patient's testimony as an instrument of their autonomy, in contrast to the technical expertise of the multidisciplinary team in decision-making processes.

## Ethical and Legal Challenges in the Context of E-Health And Data Transfer

Daniela Brešić  
KU Leuven Centre for IT & IP Law - imec, Belgium

Healthcare providers and individuals themselves are increasingly using smart healthcare devices or applications for treatment or for increasing their well-being. Such so-called 'e-health technologies' influence the way healthcare services are being performed and may entail the transfer of data between different actors (e.g. patients, doctors, private entities, and/or researchers) for different purposes. In that respect, data protection and privacy legislation (in particular the General Data Protection Regulation (GDPR)) plays an important role for the protection of an individual's personal health data by setting the requirements for the processing of special categories of data. Taking into account the involvement of different stakeholders in healthcare services, questions concerning legal and ethical challenges, such as the concept of confidentiality, may arise. The presentation seeks to provide an introduction to legal and ethical issues by examining the legal and ethical challenges arising in the context of the usage of eHealth technologies and data transfer based on literature review. To analyze the ethical challenges, the presentation attempts to apply the concept of 'Principlism' and to present how the principles of biomedical ethics by Beauchamp and Childress (i.e. autonomy, justice, beneficence, non-maleficence) could be applied.

## The Role of Ethics Committees, Ethical and Value Driven Legislatures in the Fight Against Corruption: An Analysis of the County Assemblies in Kenya

Buchere Philip Brightone, Okello Johnson  
Parliament of Kenya, Kenya

Members of parliament carry out their legislative and oversight roles in a way that is demonstrably in the public interest and do so in a way that reflects the ethical standards of their community. Surveys of public trust in professions often rank parliamentarian among the least trustworthy. Whether this reflects higher standards for people seeking public office or not, such lack of trust seriously undermines the capacity of parliamentarians to effectively carry out their duties related to corruption prevention.

Accordingly, Parliamentary ethics will continue to attract a lot of attention globally, given the increasing role parliament is gaining in holding the executive to account. The citizens expect legislators to observe ethical and deontological rules in their course of discharging their roles of law making, oversight and representation. Among their many expectations are an improved image of the legislators, improved credibility of the assemblies, and effective combating of all types of corruption. Parliamentary ethics constitutes the principles, rules and criteria for judging whether an act carried out by a legislator is in tandem with the standard rules of conduct and for assessing the motives and consequences of the act. This paper sets out to analyze the status of parliamentary ethics, ethics committees, and value driven legislatures in the county assemblies in Kenya and the extent to which they are contributing to the fight against corruption.

### **Adolescents' Autonomy to Access Sexual & Reproductive Health Services in Colombia: What do Adolescents Want? And Should it Matter?**

Julien Brisson-Morales  
*University of Montreal, Canada*

The topic of adolescents' autonomy in healthcare is ethically complicated. Adolescents are not children nor adults, yet adolescents engage in "adultlike" behavior like sex, but often have their autonomy legally framed similarly to that of children. Countries around the world have various and often very restrictive laws in relation to adolescents' autonomy to access sexual and reproductive health (SRH) services (e.g., the need for parental consent for contraceptives or HIV/STI testing). However, Colombia serves as a unique case since there are no legal age restrictions for an adolescent to autonomously access SRH services – hence, creating a context that allows exploring the emerging ethical issues related to adolescents' autonomy to access SRH services. This oral presentation will present mixed methods data collected in Colombia with adolescents (ages 10-24) on the topic of their autonomy to access SRH services. The first part of the presentation will present Colombian adolescents' opinions on their autonomy to access SRH, which unanticipatedly differs from the opinion of adolescents from Western countries. The second part of the presentation will discuss the ethical issues surrounding respecting adolescents' autonomy to access SRH services.

### **Utilizing Personal Affinity and Identification to Increase Living Kidney Donation**

Ira Brody, Atul Agnihotri  
*Kidneys for Communities / Kidneys in Common, USA*

In the United States, over 96% of all living kidney donors knew or identified with the person that they donated to. Since 2006, a single religious organization has accounted for approximately 600 living kidney donations. These people donated and designated their kidney to someone they did not know within their religious community. They created a concept that we call "Community Directed Donation". In response, a national NGO has been formed. Its mission: develop an awareness of the need for living kidney donation within specific American communities utilizing personal affinity and identification to motivate prospective living donors. Though this methodology can substantially increase living kidney donations and save lives, it relies on altruism driven by entities such as: culture; religion; race; creed; social and work fraternalism; philosophy; and other personal affinities. Some may find this concept objectionable or even unethical. Should a transplant center or a Paired Kidney Exchange program have the right to refuse the donor and recipient treatment under these conditions? We believe the trade-off is worth it as the deceased organ donor list will substantially be reduced allowing more people, without donors, to receive transplants based upon waiting time and immediate need.

### **The Ethics of Short-Term International Humanitarian Missions: Servant Leadership as an Ethical Framework**

Megan Brock  
*Ruehl School of Nursing - Milwaukee School of Engineering, USA*

Short-term international humanitarian missions (STIHMs) have become common over the last three decades and are characterized by volunteers from developed countries engaging in volunteer activities in less developed countries (LDCs) of a month or less in duration. Critiques of STIHMs abound in the scholarly literature. Some of the common criticisms are that volunteers from developed countries often display cultural insensitivity and ignorance toward the people of LDCs as well as a sense of cultural superiority commonly labeled the "Savior Complex" in the scholarly literature. Other scholarly works emphasize the development of ethical guidelines for STIHMs to obviate these shortcomings. However, none of these studies include the concept of Servant Leadership as a possible ethical framework for guiding the development and execution of STIHMs. Servant Leadership is a leadership theory that outlines several principles that are highly applicable to STIHMs, particularly Self-Awareness, or recognizing personal strengths and weaknesses; Listening, or letting those who are served define the nature of the task; and changing the Pyramid or putting those who lead in a position of service to others. Servant Leadership offers an excellent ethical framework for ensuring STIHMs are carried out in an ethical and effective manner.

### **Attitudes of Belgian Muslims towards Ethical Issues at the End of Life: A Research Program (2001-2021)**

Bert Broeckeaert  
*KU Leuven, Belgium*

Since 2001 our research group at KU Leuven university (Belgium) has been studying the views and attitudes of Muslims in Belgium regarding death and dying, with a special focus on how Muslims deal with ethical issues at the end of life. In this presentation we give an overview of the empirical methodologies used and the main results of the Islamic part of our larger research program on religion, worldview and end of life ethics. After a brief discussion of general views and attitudes towards health, illness, dying and death of male and female middle-aged and elderly Muslims in Belgium, we will, starting from the conceptual framework on end-of-life ethics we developed, discuss Muslim attitudes regarding curative and/or life-sustaining treatment, regarding pain control and palliative sedation, and regarding euthanasia and assisted suicide. At the end of our presentation, we will briefly compare our findings with the normative positions that can be found in the Islamic literature.

## How to Reduce Defensive Medicine

Daiva Brogienė  
CPME/Lithuanian Medical Association, Lithuania

The adverse effects of defensive medicine affect healthcare systems worldwide. A review of international scientific literature confirms that defensive medicine is widespread and occurs in all diagnostic-therapeutic areas. It is low-value care, which has no benefit neither to the patient and nor to the doctor. The most frequent daily practice of defensive medicine is performing more unnecessary tests and referring more patients to consultants and hospitalization. Such behavior is an ethically wrong and conflicts with deontological duties of the doctor. The practice of defensive medicine is mainly associated to the rising number of medical malpractice lawsuits. The culture of litigation negatively impacts both the medical and legal systems. Therefore, we have to speak up openly about this phenomenon and to raise awareness about this problem. The Standing Committee of European Doctors (CPME) representing national medical associations across Europe adopted the CPME position paper on defensive medicine. Recommendations on how to prevent and reduce defensive medicine in terms of cost and quality of care were made. However defensive medicine remains a controversial subject. How to prevent and reduce defensive medicine remains a great challenge for physicians and health policy makers. High value clinical practice and patient safety culture should be priorities.

## Building Community Trust: An Ethical Response to Coronavirus

Lori Bruce  
Yale University, USA

We as a global society are facing what may be a pandemic: the coronavirus, a true test of our healthcare systems. This is a brilliant opportunity for hospitals to build community trust. In response to the coronavirus, some hospitals worldwide struggle with the dilemma of keeping their community calm versus keeping their community safe. This resulted in some hospitals refraining from testing symptomatic patients out of a concern that the public would be alarmed at the sign of testing. It is wise for hospitals to try to manage the community's fears, but not at the risk of failing to contain the virus. The further that hospitals engage in oblique actions, the more community distrust will develop – and spill over into future medical encounters. These actions work against our better interests and make an assumption about the general public's ability to grasp complexity. Let's hit the pause button. Let's assume goodness and intelligence within our communities and use this coronavirus as a trust-building moment. Hospital administrators should not allow their fears to influence ethical decision-making. This talk will discuss initial responses from hospitals across the globe and how an ethical analysis of balancing benefits and burdens would have helped hospitals achieve better outcomes.

## Blurred Lines? On the Weight of the Purported Distinction Between Somatic and Germline Genome Editing from a Clinical Research and Regulatory Perspective

Carolyn Brokowski  
Yale School of Medicine, USA

The ethical and legal permissibility of human genome-editing has bifurcated. Many countries across the globe hold that such editing in somatic (i.e., non-embryonic, non-reproductive) cells is acceptable for experimentation involving human subjects at this time. Yet the majority continue to maintain that equivalent editing in the germline (embryonic and/or reproductive cells) should be prohibited. From a biomedical and bioethical/regulatory perspective regarding clinical studies, this work calls into question the normative relevance of the distinction, arguing that this dividing line—in and of itself—as a tool for deciding about the permissibility of clinical trials testing novel genome-editing technologies is lacking. This is because the purported division may fail to capture the core normative unit for determining the ethical permissibility for research involving human subjects: the risk/potential-benefit ratio. First, I briefly define and discuss the history of the somatic vs. germline distinction, addressing the reasons for the ethical (and sometimes legal) boundaries circumscribing the division. Second, from a risk/potential-benefit perspective, I show why relying on this purported distinction may be problematic—based on medical and regulatory considerations. Despite legitimate concerns about the safety and efficacy of current germline-editing technologies, blanket legal prohibitions against them are unfounded if we seriously consider risk/potential-benefit profiles.

## Due to the Aspect of Distribution Justice: Is the Discussion of a Potential Therapy in Very Rare Diseases Justifiable? A Lesson from Paediatrics

Juergen Brunner  
Medical University Innsbruck, Austria

**Background:** The complement system represents a major part of the innate immune system. A group of disorders in inflammasomes have been associated with autoinflammatory diseases (AIDs), for example Wells syndrome (MWS).

**Method:** PBMCs (peripheral blood mononuclear cells) were isolated from blood of a healthy donor and of an individual suffering from MWS. CD14<sup>+</sup> monocytes were generated. These were stimulated by addition of cytokines (IL-4 and GM-CSF) and were used for cytokine ELISAs and flow cytometric analyses. IL-6 and IL-1 $\beta$  cytokine ELISAs were performed according to the manufacturer (Biolegend).

**Results:** IL-1 $\beta$  production of iDCs is higher in the patients' cells than in the cells of the healthy donor. However, the most significant difference was shown in complement opsonized iDCs. DC-SIGN is higher expressed in complement opsonized iDCs in patient cells compared to cells of a healthy donor (37,12% v28,64%). DC-SIGN is also higher expressed in the iDCs of the MWS patient after stimulation with LPS.

**Conclusion:** The complement system may play an important role in the development of a proinflammatory milieu in patients with disorders of autoinflammation. A blockade with a Complement C5 antibody (eculizumab) may be an option. Due to the tremendous costs a discussion regarding the distribution justice might be necessary.



## Posthumanism as Legal Fiction and its Use for the Medical Law

Anna Bugajska  
*Jesuit University Ignatianum, Poland*

Together with the rapid progress in biotechnology, posthumans enter the medical legal context both as agents/doctors and patients, therefore posthumanism can be defined as an emerging legal fact. However, the relation to the "emerging fact" and the adoption of legal solutions needs the acknowledgement of a certain legal fiction, a definition of "posthuman" which does not yet exist and making a set of assumptions on the posthuman character, nature, capacity, etc. as evident, for example, from the debate about the "posthuman rights". Legal fiction, notoriously understudied in medical law, is a normative solution which assumes that a legal fact has indeed occurred without either empirical evidence or sufficient justification. It remains in co-dependence with moral fictions, and both in turn have real impact on the shaping of policies and codes of conduct. Legal fictions might become utopias or dystopias and they may become part of narration. They are helpful in facilitating legislative processes, but may also be harmful, creating false frameworks. In my paper I discuss the justifiability and possible consequences of adopting fictions in medical law in relation to posthumans, such as genetically modified babies, organoids, biohackers, and medical robots.

## Living Organ Donation: Young Donors, Kidney "Voucher", Euthanasia Candidate as a Living Organ Donator

Jadranka Buturovic-Ponikvar  
*University Medical Center Ljubljana, Slovenia*

In 2018, 27.5% kidney transplants in Eurotransplant and 30.4% in US were from living donors. However, donors may be subjected to family pressure and call to sacrifice (Nancy Scheper-Hughes, AJT 2007). In Canada 16-year-old can legally donate a kidney (Campbell, AJT 2013). Public solicitation for organs (mainly through social networks) is allowed in US, Canada, UK, the Netherlands (Pronk, Transplant Int 2018). It can be turned into a version of the "beauty contest" or involve hidden organ trafficking.

Recently, "voucher" kidney program donation has been introduced: donor wants to give kidney to relative, who does NOT need a transplant at a time. So, donor donate a kidney to nonspecific recipient in a chain and relative receives a "voucher" to have priority in the future, if being in need of kidney transplant (Veale, Transplantation 2017).

There are initiatives to abandon dead-donor rule and use euthanasia candidate as a living donor, with heart harvesting being the final act of euthanasia procedure (Savulescu, Bioethics 2012, Bolle, J Heart Lung Transplant 2019).

Conclusion. Ongoing or proposed practices in the area of living organ donation should be closely monitored, with special focus to protect young and most vulnerable members of the society.

## A Critical Perspective on the Transparency Issue of the Medical Implementation of Artificial Intelligence

Banu Buruk, Perihan Elif Ekmekci  
*TOBB ETU School of Medicine, Turkey*

Artificial Intelligence (AI) is among the fastest developing areas of advanced technology in medicine. AI is able to improve its original program and decision-making algorithms via deep learning abilities. This autonomy makes AI unique among all other advanced technologies in terms of ethical issues. Confidentiality, security, responsibility, equality, accountability and transparency are at the forefront of ethical issues associated with AI. Among these, transparency is of particular importance because it can lead to different ethical problems in different dimensions. For example, user transparency is often overlooked in the context of different dimensions of transparency. User transparency problem gains a different context in healthcare. In this study, user transparency in the field of health will be analyzed with respect to ethical principles and values. Physicians, nurses, care-givers and patients are the users of AI technology. The aim of this study is to make a correlation between two concepts: user transparency and vigilance, which we call it "AI-vigilance" and, evaluate the responsibilities of users in terms of this new concept. Our final task is to pursue a discussion in terms of the ethical dilemmas about AI-vigilance issues occurring in practical life.

## Day to Day Physician Work: Moral Decision Making and Administrative Awareness

Chen Buxbaum  
*Rambam Health Care Campus, Israel*

The primary role of a physician is to determine the correct diagnosis and apply the appropriate treatment. However, during the daily routine of caring for hospitalized patients, physicians can take part in and facilitate many other aspects of patients' care, including ethical-legal ones, that may greatly change a patient's course of hospitalization.

The following examples of relevant initiatives we undertook in 2019 will be presented in this talk:

The creation of a unique form, that stimulates and direct the physician to accounted for all the procedures a non-competent patient may need during hospitalization that require informed consent, allowing for a more coherent and efficient guardianship nomination process; Presurgical evaluation and appointment of a proxy decision-maker, for patient destined to undergo urology surgery, that are prone to changes in the surgical plan.

To our satisfaction, we were able to institute these changes fairly easily, and many patients and families are now able to enjoy their benefits.

## Ethical Conflicts Arising from Cultural Differences at the End of Life: Assisting Migrant Patients

Lucía Higuera Cabañes<sup>1</sup>, Nuria Pérez de Lucas<sup>2</sup>, Antía Fariñas<sup>3</sup>, Ana Bravo<sup>2</sup>

<sup>1</sup>Villa de Vallecas Health Center, Spain

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<sup>3</sup>San Rafael Hospital, Spain

The society we live in is a multicultural one and therefore there exist multiple ways of understanding death. This fact determines the attention that palliative care specialists provide to people at the end of their lives. It is essential to broaden our gaze in order to handle cultural, religious, economic or communication problems.

The objective of this work is to analyze the ethical problems that may arise when working with immigrant population and terminal illness.

To this end, we present the case of a Moroccan patient resident in Spain. He was incapacitated by a severe psychic disability and a terminal kidney disease. Prior to his death, the whole team faced the ethical problem in which their desire to protect the patient's well-being came into conflict with his autonomy (transferred to a family member) to decide how and where to die.

The analysis of the case surfaced important aspects. Firstly, the importance of understanding the values and preferences of patients and their families in their different cultures. Secondly, teamwork was found to be critical in the successful outcome of this case. Finally, the deliberative method demonstrated to be an invaluable tool for shared decision-making in these situations to achieve a humanized death

## Medicalization of Social Policies: Nazi Roots, Contemporary Continuations

Amanda Caleb

Geisinger Commonwealth School of Medicine, USA

This presentation examines the process of medicalization during the Nazi regime and the continued relevance in contemporary social policies. Medicalization is the process of framing a social problem as a medical condition, thereby identifying the source of the problem as one of individual accountability and emphasizes the need to treat or cure the individual. When applied to social policies, this framework perpetuates dividing practices that create categories of social health and social sickness and allow for the control of individuals and groups of individuals. Nazi social policies were grounded in their racial hygiene agenda, which meant medicalizing individuals who participated in so-called deviant behavior, who contributed, or failed to contribute, to the nation's welfare, and who were considered a threat to the citizenry and the health of the nation. This same medicalization of social policies is evident today in countries' approaches to regulating sexual and criminal behavior, limiting government assistance, and restricting borders.

## When Identity is for Sale: Genetic Ancestry Testing, Informed Consent, and Diasporic Social Justice Concerns

Shawneequa Callier, Vanessa Northington  
George Washington University, USA

Consumer genomics companies such as 23andMe and Ancestry.com provide a dual-facing business model that engages consumers as well as large companies that purchase aggregated data. The genetic ancestry testing services provided to consumers are based largely on reference data comprised of individuals of European ancestry. To capture more diverse data, companies are encouraging global participation in genetic ancestry testing. As consumers in developed countries help to build companies' data sets by purchasing genetic testing services, it is unclear that they understand the limitations of these platforms for consumers with non-European ancestral histories or the impact on distant relatives in low- and middle-income countries. This presentation will explore the international bioethics issues related to genetic ancestry testing and data aggregation involving consumers of the African diaspora and assess informed consent and social justice concerns raised by these biotechnologies.

## Children & Youth's Right to Participate in Health Policy Discussions: A National Government's Moral Responsibility?

Sydney Campbell  
University of Toronto, Canada

In 1989 the UNICEF Convention on the Rights of the Child (CRC) came into effect with the goal of protecting and fulfilling the rights of children around the world. Amongst other rights, the CRC prioritizes the right children have to participate in discussions and decisions that have impact on their lives. Though the CRC is the most widely ratified human rights treaty in history, evidence suggests that encouraging children and youth's involvement in policy-level discussions is often still absent, despite various national plans to include youths' voices. When it comes to health contexts, the voices of young people seem to disappear even further in policy discussions, resulting in an additional level of silencing in an already adult-centric world. Thus, the question becomes: what level of moral responsibility do those governments and institutions who have ratified the CRC have to ensure members of the paediatric population are involved in discussions that have the potential to impact them, particularly in health contexts? My presentation will examine this question and posit that these governments have a strong moral duty to implement laws and forums related to the CRC that necessitate listening to the voices of children and youth and providing young people with opportunities to share their thoughts and concerns on health policies that impact them, even (and especially) on a national scale.

## Aristotelian Ableism in Medicine

Tiffany Campbell  
University of Utah, USA

In this paper, I introduce the concept of Aristotelian Ableism and show how it has infected modern medicine. Aristotelian Ableism is a unique form of ableism that manifests itself as the belief that only bodies with intact capacities can achieve flourishing. Aristotelian Ableism can be found in medical practice, particularly in disciplines connected with reproductive counseling. However, Aristotelian Ableism has a fundamental flaw. Aristotelian accounts of human flourishing depend on teleology, which tells us that the purpose of an x is its function, and Aristotle's ergon argument, which states that a good x is an x that functions well. Aristotle writes that what is true of the parts should also be true of the whole. However, making the move from judgments about the goodness of physical parts of a human body to moral evaluations about that body's capacity for flourishing, the (Aristotelian) function of a human life, is a serious mistake. A close reading of Aristotle suggests that if disabled people are assumed to be fully human, then Aristotle's conclusions about flourishing are likely incorrect. With that flaw exposed, I return to the instances of Aristotelian Ableism in modern medicine to show how the fundamental flaw can be diagnosed there.

## A Death Due to Relapsing Multiple Myeloma Complicated with Metastasis and Co-Infection with Bone Tuberculosis

Awa Carimo, Emilia Pinto  
Maputo Central Hospital, Mozambique

53-year-old female admitted several times with chronic renal failure due to multiple myeloma after completion of chemotherapy. Her main complaint was back pain and neuropathic pain of the lower limbs, refractory to several analgesics, including opiate derivatives.

**Comorbidities:** major depression with episodes of psychosis, chronic anemia requiring multiple blood transfusions, and an osteopenic bone disease. She denies hypertension, diabetes and previous transfusions.

**Physical Examination:** good general condition, poor nutritional status. Apyretic, anemic, tachycardic, without dyspnea; normal blood pressure, no crackles, no murmur, with a Gallop rhythm. Neurological examination: cauda equina syndrome.

**Studies:** Hemoglobin 5.4g/dL, WBC 6.18x10<sup>9</sup>/L, Platelets 187x10<sup>9</sup>/L, ESR 130mm/H, HIV negative, BUN 67umol/L, Creatinine 3.278umol/L, calcium 2.8mmol/L, Phosphate 3.5mmol/L, uric acid 2.45mmol/L. Abdominal ultrasound- poor cortico- medullary differentiation in both kidneys with normal size; X- ray and MRI- multiple vertebral destruction and lumbar paravertebral abscess.

**Therapeutic Plan:** dialysis, erythropoietin, analgesics, amitriptyline, vitamin supplements and calcium carbonate. Antibiotics. Per neurologist opinion, tuberculosis treatment was initiated with improvement in abscess size. Her follow up in the next 5 years showed that the myeloma was reactivated and she started maintenance treatment with thalidomide until she died in 20 August 2018 with bone and cerebral metastasis

## Development and Implementation of an Institutional Curriculum in Ethics and Public Health in Cuba

Roberto Cañete Villafranca<sup>1</sup>, Katia Brito<sup>1</sup>, Dirce Guilhem<sup>2</sup>, Maria R Novaes<sup>2</sup>, Kenneth Goodman<sup>3</sup>

<sup>1</sup>University of Medical Sciences, Cuba

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<sup>3</sup>University of Miami, USA

Bioethics teaching has traditionally focused on classroom activities, but there is a widely recognized need for professional development opportunities for people with active scientific, clinical or administrative duties. Moreover, there is a shortage of evaluations of ethics programs and curricula. In this cross-sectional study, we surveyed hygiene, epidemiology and microbiology professionals who attended 17 ethics courses in Matanzas province, Cuba. The curriculum consisted of 2 main themes: research ethics and public health ethics. The survey comprised pre- and post-test assessments and in-depth interviews of all participants 3 months after the end of each course. Most attendees (i) appeared to demonstrate increased knowledge in research and public health ethics, including international guidelines, (ii) gave positive assessments of the courses and (iii) affirmed the importance and pertinence of such training activities. This study is suggestive of the kinds of professional development opportunities available in limited resource settings.

## The Virtue Bioethics and Its Interface with the United Nations 2030 Agenda: Possible Dialogues with Health Promotion in Higher Education

Ivaní Nadir Carlotto, Maria Alzira Pimenta Dinis  
University Fernando Pessoa, Portugal

**Background:** Establish connections between the principles related to virtue bioethics, the goals set by the 2030 Agenda, and health promotion (HP) applied to university teachers. The 2030 Agenda, in its SDG 3 - Ensuring a healthy life and promoting well-being for all at all ages, allows us to reflect on the connections between the virtue bioethics paradigm and HP. Both value the interactions between individuals and envision the operationalization of health actions involving well-being, quality of life, solidarity and empathy, since the human person is seen as a being in continuous development and respected in their integrity and experiences.

**Objective:** To identify the interfaces between virtue bioethics and the 2030 Agenda as a substrate for the development of bioethical interventions in HP in higher education.

**Methodology:** Exploratory-descriptive, quantitative-qualitative approach, random sampling with university professors, not probabilistic for convenience, n = 1400 teachers. Approved in the ethical instances and CAAE 55066616.8.0000.5327.

**Results:** Extraction of 6 main components through categorized factor analysis and interpreted by qualitative content analysis.

**Conclusions:** Principles such as respect for personal dignity, protection, sustainable health actions, peace, solidarity and empathy were perceived by teachers, with a positive impact on their health. These characteristics are associated with the virtue bioethics and HP and correlated with 2030 Agenda in their SDGs.



## Short-Term International Humanitarian Missions: The Scholarly Debate

Victoria Carlson-Ohlers, Patrick Jung, Bernard Cohen,  
Kathleen Miezio  
*Milwaukee School of Engineering, USA*

Short-term international humanitarian missions (STIHMs) from developed to under-developed or emerging developed countries, have increased over the past two decades. Medical, engineering, and construction projects are most common. Two schools of thought have emerged in the scholarly literature concerning STIHMs.

The first argues STIHMs result in more harm than good for the residents of host countries and that STIHMs are merely a form of "VolunTourism" that serve as "feel good" experiences for participants. Moreover, many participants demonstrate a sense of cultural superiority that scholars label the "savior complex." The principal weakness of these works is they tend to focus on a single STIHM that may have been poorly planned with little follow through.

The second asserts STIHMs can benefit both participants and the residents of host countries when preceded by instruction concerning the host countries' cultures. Also important is instruction in ethics, which obviates the savior complex. Finally, STIHMs, when properly planned and executed, fulfill Articles 12 and 13 of the Universal Declaration on Bioethics and Human Rights, which call for the promotion of cultural diversity and pluralism as well as global solidarity among human beings and international cooperation. These scholarly schools of thought will be discussed in detail.

## Conflicting Rights and Interests in Reproductive Choices: When Parents Want to Choose the Genetic Characteristics of Their Child

Aur lie Cassiers  
*U Hasselt, Belgium*

The development of biotechnologies allows us to make more and more choices in the procreation process. Nowadays, medicine not only helps people to conceive, but also select which child they want with the help of e.g. preimplantation genetic diagnosis, prenatal tests, and even, as science advances, choose many of the child's characteristics with the use of CRISPR-cas9. Parents may be happy to have more control over their reproductive possibilities, but is this development a good evolution for everyone? Other interests, like these of the (unborn) child and the society, may be in danger. Even if some authors pretend that it is in the best interest of the child to be born with the best possible genetic background, others warn for negative consequences for the children's right to life, for the child's dignity, for the equality and non-discrimination in society, for the rights of minority groups such as disabled persons, for the future of the human race, etc.

In this presentation, we will examine the relevant ethical principles and the rights concerning three important groups of interests, namely the child, the parents, and the society.

## Recent Portuguese Case Law on Informed Consent

Ana Carvalho<sup>1,2</sup>, Isabel Po as<sup>3</sup>

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Informed Consent, clarified and free, is a form of expression of will that is intended to respect the right of the user to decide on his health, and it is essential that there is adequate information so that consent is truly clarified, namely as to the purpose and nature of the intervention as well as its consequences and risks. In the Portuguese legal system, there are several rules that protect the need to obtain informed consent of the patient, namely Article 5 of the Convention of Human Rights and Biomedicine (Oviedo Convention), Article 3 of the Charter of Fundamental Rights of the European Union, Articles 25 and 26 of the Constitution of the Portuguese Republic and Article 70 of the Civil Code. Violation of informed consent is a violation of the patient's personality rights and may, in particular, give rise to civil liability. With this Communication we intend to present recent selected cases of national case law on the violation of informed consent and the consequent civil liability, in order to promote an informed, free and clarified consent towards the practice of medical and similar acts.

## Evolution of Brazilian Bioethics after the Doctoral Program Federal Council of Medicine Agreement with the University of Porto

D bora Eug nia Braga N brega Cavalcanti  
*University of Porto (FMUP), Portugal*

Since 2007, the Federal Council of Medicine of Brazil and the Faculty of Medicine of the University of Porto have entered into a partnership for the creation of the FMUP / CFM Doctoral Program in Bioethics, coordinated by Professor Rui Nunes. The postgraduate course has been modifying medical practice regarding medical ethics and bioethics, the program has been encouraging students to effectively build successful performances and discussions in professional and academic circles. The present study seeks to report that the health professionals who take the course go through a watershed in their medical professionals, due to the studies and practices developed during the course. Bioethics is a recent topic, so there are several complementary concepts that have been materialized among researchers and specialists. The professionals who participate report better understandings to understand and solve paradigms in contemporary society, those paradigms that are installed not only in the area of health but in human ethics, in the search for peace in the world, ecological preservation among others. It is observed that the professionals who attended postgraduate studies in bioethics report a new position in their professional performance, being evaluated as more beneficial to society.

### **Neonatologists' Ethical Decision-Making for (Non)Resuscitation of Extremely Preterm Infants: Ethical Principles, Challenges and Strategies**

Alice Cavolo<sup>1</sup>, Bernadette Dierckx de Casterlé<sup>1</sup>, Gunnar Nauelaers<sup>2</sup>, Chris Gastmans<sup>1</sup>

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Uncertainty of outcomes makes it difficult to decide whether to resuscitate extremely preterm infants (EPIs). Ethical questions quickly arise: should we always prolong life as much as possible? Is palliative care better in some cases? The ethical literature says that EPIs' best interest and respect for parents' autonomy should guide the decision-making. However, it is unclear whether neonatologists actually use these principles to decide and how they use them. To understand that, we interviewed 20 neonatologists working in 10 NICUs all-over Belgium.

We found that neonatologists consider different principles depending on what is applicable in each case. However, they try to balance EPIs' best interest and respect for parents' autonomy in every single case. How they balance them depends on gestational age. Outside the grey zone, the leading principle is the best interest; inside the grey zone the leading principle is parents' autonomy.

Unsurprisingly, conflicts between these principles were the main ethical challenge. Conflicts occurred when interviewees believed that parents' request was against the EPI's best interest. Neonatologists struggled understanding whether overriding parents' autonomy was ethically appropriate and how to do so in a sensitive way. When attempts to find an agreement with parents failed, they developed moral distress.

### **The Interest of Third Parties in Genetic Research: Are we Owners of our Genetic Data?**

Juan Ignacio Cerdá Meseguer  
University of Murcia, Spain

Inherited or acquired genetic data can provide information about the physiology and health of a person. Genetic research in the area of healthcare is essential to find out how and why a disease develops or its behavior, as well as a way to make progress on treatments that allow its cure more effectively and even anticipate its development.

In this context it was stated that in many instances and particularly in diseases that have a genetic and hereditary component as a determining factor, the possibility of having access to genetic data of different members of the same family may mean that results are obtained in order to benefit not only these patients but many others who may develop the same disease. Do we own our genetic data to the point where we can dispose of them to the detriment of the interests of third parties, in this case other direct family members? Can we refuse to give our genetic data over for scientific research? Is there a general interest that justifies the use of data to make progress in the treatment and cure of a disease? In what conditions?

This paper will offer the terms in which this debate can be raised from the legal perspective and, in particular, the analysis that is necessary to carry out in order to establish the conditions that allow dealing with the tension that exists between the different legal assets in conflict.

### **Patient's Rights: A Global Care for all the Family Inside and Outside the Hospital**

Lucia Celesti, Massimiliano Raponi  
Pediatric Hospital Bambino Gesù, Italy

The authors describe the hospital services specifically dedicated to the patients and their families in order to provide them a 'total care' system. Being sick is tough, even tougher when a child is sick. Even harder is the moment when the young patient and his family have to move to another City or Country, because of the rarity and complexity of the sickness. Besides the continuity of clinical treatment for the young patient, the continuity in the family's care is also needed.

A very small number of Hospitals are organized to support family needs considering the global care of the family as a critical factor for therapy. In this regard, through the constant analysis of the needs of families, Bambino Gesù Children's Hospital in Rome has emphasized the importance of building a Family Service organization to protect the patient and his family from the traumatic effects of hospital admission. Family Services are specifically meant to take care of the child and his family for all the non-clinical aspects of assistance, whatever fundamental: a real "therapy of care".

### **Clinical Trials Involving Minors: The Role of the Ethics Consultation in Avoiding Therapeutic Misconception**

Silvia Ceruti  
Italy

Therapeutic Misconception (TM) occurs when clinical trial participants believe that the central purpose of the trial is therapeutic and that they will personally benefit from participation.

If individuals who are entitled to consent to participation in a specific clinical trial do not understand that the defining purpose of clinical research is to produce generalizable knowledge, regardless of whether the subjects enrolled may potentially benefit from the intervention under study, this false belief may motivate them to participate, and in extreme cases may disqualify their consent.

TM is especially frequent in fields in which the patients are highly vulnerable, such as when they are children and require parental consent. The informed consent is an essential ethical prerequisite before enrolling each and every participant in research, that should protect patients through a process of dialog about a planned course of action.

We argue that Ethics Consultant's competencies may be crucial in avoiding TM: The Ethics Consultant should be involved in neonatal and paediatric clinical trials in order to face the unique vulnerability of children as research subjects, and to ensure that parental consent procedures are rigorously managed, enhancing recruitment in research trials in the context of fully understood consent.

## Child Sexual Abuse, the Holocaust, and Doctors: Ethical Responsibilities for Respectful Care

Beverley Chalmers  
Perinatal Health Consultant, Canada

Seven categories of disrespectful care of women by healthcare providers, including sexual abuse, are identified by the WHO. Homophobic, antisemitic and sexually charged comments are made by doctors in operating theatres with little done to stop them. Recently, sexual abuse by doctors caring for young athletes, such as Larry Nassar, hit world headlines. It is not surprising – although to date unacknowledged – that sexual abuse of children, including – occasionally – by doctors, also occurred during the Holocaust.

Mengele, in Auschwitz, showed a salacious interest in the sexual activities of the Lilliput family of entertainers comprising seven dwarfs and their normal size partners. Child twins in Auschwitz and in Mauthausen testified that they were forced to have sex with other twins as part of medical experiments. In Buchenwald, at least one teenager was sexually abused by a doctor.

Hundreds of children were sexually abused in the Holocaust, not only by doctors, but by people in positions of authority, who had opportunities, little fear of discovery, or of negative repercussions. Lessons from the Holocaust can sensitize doctors to their ethical responsibilities to provide respectful care, and the potential for abuse, including sexual abuse, that their positions offer and sometimes facilitate today.

## Conscientious Objection and Abortion: Prevalence, Perceptions and Protocols

Saumya Chanana  
Bond University, Australia

Healthcare practitioners can conscientiously object and refuse to provide medical interventions if they deem them incompatible with their moral, religious, philosophical or ethical beliefs. The foundation of conscientious objection (CO) is based on the fundamental value of protecting moral integrity, allowing practitioners to practice in accordance with their conscience and central identity.

There is much debate regarding CO in the fields of euthanasia, contraception, assisted reproduction, sterilization and abortion – with abortion generating the largest conscientious objection status worldwide. Conscientious objection to reproductive healthcare is largely understudied with quantitative and qualitative empirical research lacking therein and has made estimating the prevalence of conscientious objectors difficult.

As moral agents, practitioners may encounter a conflict between their personal conscience and their professional responsibility to patient care. Whilst practitioners have the right to CO in democratic states, its practice must consider this underlying tension. The empirical impacts of CO on patients, both at an individual and systemic level are often not adequately considered – with an impact on their autonomy and overall justice.

A literature review of qualitative and quantitative research was conducted to synthesize current evidence of prevalence, perceptions and protocol structures as basis for this presentation while emphasizing the need for more education.

## Telehealth and the Opportunity to Enhance Patient Health Literacy

Lukas Chandler  
Georgetown University, USA

Telehealth changes what it means to be “seen” in a medical context by holding the clinical consultation via videoconferencing. This clinical modality equips healthcare providers to reach underserved populations for specialty, continuous, and episodic care. Telehealth further presents an opportunity to enhance patient health literacy. By conceptualizing health literacy as a general capacity, we may advance a framework in which a patient's agency is acknowledged, genuinely respected, and concretely empowered through the care delivery platform of telehealth. This presentation demonstrates how telehealth unveils a new angle to the timeworn bioethical questions concerning trust and rapport-building in patient-provider relationships, and how this context is an opportunity for patient education in clinical consultations held at a distance. Through telehealth videoconferencing, health literacy may be fostered and enhanced via the communicative vehicle of shared decision-making in the patient-provider relationship. This presentation illustrates the context of chronic care management where provider and patient are no longer the only actors with interests in clinical relationships. Remotely delivered healthcare may influence patient education and health literacy. It may also address current challenges within the clinical encounter and provide potential answers to ethical issues with healthcare experienced at-a-distance.

## City of Women: Graphism as a Tool for Effective Sexual and Reproductive Rights

Maria Clara Chaves  
Federal University of Rio de Janeiro, Brazil

The history of the city is told through the experience of diversified subjectivities that unravel in themselves a geographical wisdom inherent in the urban agglomeration. A historicity pervaded by places and non-places, hegemonic spaces of power and resistance to seize the city and its occupation. Urban art and graffiti act as apparatuses for the realization of women's rights, such as the right to the city or even the possibility of using artistic ways to achieve access to knowledge and contact with these rights.

The objective is an examination of graffiti as a tool for the realization of women's sexual and reproductive rights, from an intersectional gender and health bioethics perspective, in which urban art can assist public policies in collective health. Thus, understanding women's autonomy in this process of managing their bodies and in the exercise of their subjectivities is fundamental.

The analysis presented stems from the social changes provided by the multifaceted urban dynamics of cities, such as Rio de Janeiro/Brazil, which transgress the heteronormative character of women's location in a capitalist system. However, the crossings that permeate women's subjectivity and body reveal androcentric factors that perpetuate the asymmetries for the realization of women's sexual and reproductive rights.

Therefore, it is necessary to rethink the rationality underpinning the understanding of women's health demands from a gender bioethical perspective.

## **Announcing the Lancet Commission on Medicine and the Holocaust: It's Time to Teach**

Tessa Chelouche  
*Technion - Israel Institute of Technology, Israel*

During the past 20 years the connection between medicine and the Holocaust has been taught only in a small number of medical schools, and those few professionals involved in the field have worked for this to be included in the medical curriculum worldwide. This has not happened and for decades the medical community has not engaged with the uncomfortable questions that arise from this history.

But this may be about to change. In February 2021 we announced the formation of the Lancet Commission on Medicine and the Holocaust: Historical Evidence, Implications for Today, Teaching for Tomorrow. Among the many aims of the two- year commission are to debunk the myths surrounding the Nazi physicians, to explore the relationship between physicians and the Nazi state, to examine the role of physicians as perpetrators, and to identify areas vulnerable to abuse of power in medicine. Another important objective is to develop a road map for the inclusion of this history in medical curricula which can provide the opportunity for reflection on the role of the physician in society, on the importance of human dignity, would promote ethical conduct and moral professional identity development.

## **The Horizon in the Establishment of the UNESCO Ethics and Religion Department**

Yuval Cherlow  
*The Zohar Rabbis Organization, Israel*

The encounter between ethics and the world of religions is one of the most fascinating and significant. On the one hand, an integral part of the motivation to do what is right and good can come from religious motives. Not only that, but religions also have many references to the ethical content of the various issues. On the other hand, due to the fact that the essence of religion includes a commitment to God - conflicts sometimes arise between religious and ethical worlds.

Another layer of importance of this meeting is the fact that a huge portion of the world's population believes in one form or another in God, and therefore also considers religious considerations in the context of his medical activities.

There is therefore a great need for a framework to deal with the fascinating issues between ethics and religions.

The presentation will present examples of the encounter between ethics and religions, various bioethics dilemmas, and special attention to the ethics of religious practitioners. Going forward, we'll deal with a few options to create a compass for these dilemmas.

## **Organ Donation: Should a Presumed Consent Be Sufficiently Informed?**

Kartina Choong  
*University of Central Lancashire, UK*

England will embrace an 'opt-out' legislative framework when the Organ Donation (Deemed Consent) Act 2019 comes into force in 2020. Competent adults who have ordinarily resided in England for at least 12 months who do not register their refusal to be organ donors, will thenceforth be presumed to have given their consent to the retrieval of their organs after their death. However, is this 'presumed consent' sufficiently informed? In other words, can we be confident that the inaction of those not objecting to having their organs retrieved is attributable to the information they have, rather than to the information they do not have? Commentators have highlighted that the discourse between organ procurement organizations and the public is frequently characterized by self-interest. Thus, only information favorable to organ procurement are usually disseminated. If this were true, then the need for a higher level of information disclosure is arguably warranted in a presumed consent legislative framework as organs would be retrieved from people who have not expressly consented to it. These would include the need to inform them that the body could still be ventilated and thereby 'living' when the organs are retrieved; and that death is diagnosed using neurological criteria.

## **Ethics Committees, the Right to Health and the Right to Benefit from Scientific Progress**

Didier Coeurnelle  
*Heales (Healthy Life Extension Society), Belgium*

Diseases related to old age are responsible for 70 % of deaths worldwide and 90 % in countries like Portugal or the USA. The only way to prevent illnesses linked to aging is to attack the root cause – that is aging itself. In the world, the ethical committees (called IBR in the US) are working to protect volunteers from unethical practices, but not enough to promote research useful to all.

How to inform ethicists? We should consider research for a longer life as a moral obligation, a duty to rescue, a guarantee for a better future world. This is an application of the right to share in scientific advancement and its benefits (article 27 UDHR).

Ethicists should favor the possibility for well-informed citizens to make clinical tests for longevity especially in the following fields: Genomics and gene therapies, senolytics, stem cells, restorative nanotechnologies. The current state of aging research, especially in the US and in countries of the EU is promising. There are improvements necessary for the legal and ethical frameworks of the committees. This concerns the rules making it more difficult (where it should be easier) for older patients to take part in clinical tests and for well-informed volunteers and for scientists developing innovative theories to start clinical tests rapidly.

## Is Contraception Enforceable? Ethical Dilemmas with Persistent Pregnancy Wish in a Woman with Mild Mental Disability, Who Was Deprived of Her Parental Rights

Dan Cohen

MHO North-Holland North, Netherlands

We present a case of a single, 26-year-old women with mild intellectual disability (IQ 65), who neglected prenatal care and was deprived of parental rights of her 2 and 4 years old children. Her persistent desire to have a child and raise it, keeps her from accepting contraception. All attempts and arguments about her permanent inability to raise children fall on deaf ears.

Debate. In 2002, a Dutch governmental commission advised more education, more extensive provision of information and further investigation. No standpoint was formulated about the ethical dilemmas present in this case.

Arguments against enforceable contraception are the universally acknowledged autonomy of each person and respect for the integrity of the body.

Arguments in favor of forced contraception are reduced decisional capacity and self-assessment, due the mild intellectual disability. Secondly, reduced capacity of realizing long term consequences of decisions. Thirdly, patients' lack of fair judgment of her educational impairments.

Arguments related to the child: the mother is single, with no paternity in sight. Secondly, an increased risk of a mentally disabled child. As chances are high that the mother will again be deprived of her parental rights, the child will grow up without biological parents.

## Protected Health Information Vulnerability in Telemedicine

Bernard Cohen

Neurological Monitoring Associates, USA

By 2020, there may be 50 billion devices connected to the Internet of Things (IoT). More of these will be WiFi-enabled and handling medical data and protected health information (PHI) for which there may be huge penalties for non-compliance.

The medical industry is one of the fastest growing areas implementing Big Data utilization of IoT and hence most susceptible to invasion from outside forces. The value of hacking medical data far exceeds that of hacking financial institutions.

We use telemedicine to monitor critical real-time data from high-risk surgeries. It is crucial our data is free of interference and cross-talk. The IoT demands giving rise to 5G technology must be extremely robust protect against hacking. We partner with a commercial vendor of remote connect software to create, we believe, is a highly protected system. We use double rolling code authentication, run parallel secure VPN servers, external mains power backup, and each with redundant AI firewalls that are constantly "learning" from "attack" programs.

This configuration has had no incidents of malicious-ware escaping detection. Safety and security of medical data is a bioethical mandate as addressed in Article 9, "Privacy and Confidentiality," of the Universal Declaration on Bioethics and Human Rights.

## Time to Electronic Communication in Ethics Committee: Experience & Challenges

Ornit Cohen<sup>1</sup>, Michal De-Wolf<sup>1</sup>, Anat Engel<sup>1</sup>, Alon Roiz<sup>1</sup>, Shimon Narkis<sup>2</sup>

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**Background:** Independent Ethics Committees (IECs) play a key role in the oversight of clinical trials. The current functioning of IECs involved a significant amount of paperwork, increasing the routing and storage costs and extensive time in training new personnel.

We aimed to change the local IEC office and committee to electronic communication and storage within 6 months at a medical center.

**Methods:** Start, July 2019, the entire clinical studies paper-binders were scanned and store out of the IEC tiny office. During the meeting, IEC members moved to electronically read of submitted studies via Tablets instead of using a huge amount of paper -binders every meeting.

A new SOP of using the "Matarot-Care" module used to assists in managing new studies submission and continuing modification along with the study electronically.

**Results:** Over 500 binders were scanned and stored. A new submission is a transfer electronically by internal mail instead of twelve hardcopies. After the IEC meeting ends all confidential materials are deleted and no paperwork left. Sign approval scanned within 2 days.

**Conclusion:** Electronic IEC (eIEC) may achieve an automated system that holds benefits such as electronically create, modify, and submit review board documents, facilitates electronic development of meeting agendas and minutes, Use a standardized template and reports workload, approval time, and productivity metrics. Moving to eIEC attain part of the dream of being paperless and perform the regulatory work almost without a printing paper in efficient way.

## Nursing Ethical Discussion: Is it Possible in Times of Economic and Resource Scarcity?

Hagar Cohen Saban, Gila Hyams

Rambam Medical Center, Israel

Nurses' responsibilities and tasks have grown as the medical practice develops and the digital medicine revolution is expanding. Hospital management is exploring ways to ensure a good quality care and excellent service to their patients while managing operational excellence (van den Oetelaar, Van Stel, Van Rhenen, Stellato, & Grolman, 2016). Therefore, ethical considerations in nursing care must be applied to the realities of nursing and health care in particular settings (Stievano & Tschudin, 2019).

Nursing management views ethical discourse as an integral part of nursing practice. In our organization we aim to develop an ethical leadership approach in nursing to promote critical ethical thinking. Therefore, a forum of Nurses is convening. We use inside forces to promote the ethical discussion and save the ethical debate spirit and enthusiasm within our staff.

The forum meetings include ethical topics presented by leading people in the field, for example - dilemmas in the treatment of children from the battle areas in Syria, ethics and health economics. Each session is divided into two parts, with the second part presenting dilemmas presented by forum participants on topics related to the clinical areas in which nursing staff work. The discussion takes place in small groups, the meetings are held once a month, for two hours and are open for every nurse in the hospital.



## Intercultural Medicine and Plural and Democratic Society

Natasha Cola  
*Università Degli studi di Genova, Italy*

Intercultural medicine is a fundamental element of sustaining a plural and democratic society.

It raises questions at methodological, ethical-social, managerial and staff training levels that bring into play the principle of equity to which the National Health Systems should refer.

At the international level, also thanks to the initiatives undertaken by the WHO, a substantial part of literature has been oriented towards the study of the way and practices of integration between indigenous and western medicine and communication processes. Whereas until now, studies on the vision and symbolic meanings of the different cultures of the healing process and disease, the perception of pain and the vision and meanings attributed to birth and the end of life appear less developed. This reflection necessarily obliges us to take into consideration two problems which are connected, important and currently scarcely investigated: the

commensurability/incommensurability between cultures and the translation/translatability of terminology of the care process from one culture to another. One possible solution consists in the creation of new languages that can enable both health professionals and society in general to create a model of responsible and inclusive co-partnership that includes intercultural medicine.

## The Late Suicide of a Treblinka Survivor: Ethical and Educational Lessons in Mental Health Care

Kenneth Collins  
*The Hebrew University, Israel*

The life, health and death of Hershl Sperling (1927-1989), a survivor of two death camps and five concentration camps, has profound lessons for mental health care. His experiences in Treblinka were documented in a short account in Yiddish in Munich (1947) and augmented in a detailed biography (2010). Sperling was born in Klobuck, a small town near Czystochowa, from where he was deported to Treblinka in August 1942. The only family survivor, he endured brutal, grueling and emotionally draining tasks in the extermination camp and was one of the few survivors of the final desperate prisoner break-out. Arrested soon after, he arrived in Auschwitz identified as an ethnic Pole. Auschwitz, as a Polish political prisoner, represented a far lesser terror than his experience of Treblinka, despite brutal punishment in the strafkompanie. Later, he would be increasingly disturbed by those who could not understand this 'lesser terror'. Settling in Scotland after liberation from Dachau his mental balance became upset leading to suicide at the age of 62 years. This paper traces his story, covering the tragedy of his teenage years, his emotional failure to escape the past and draws significant lessons from his, and his sons', lengthy struggles with psychiatric treatment.

## Perception of physicians regarding Mental Health Care in Primary Health Care in Poços de Caldas City - Brazil: perspective of Bioethics

Euclides Colaço Melo Dos Passos<sup>1,2</sup>  
<sup>1</sup>Pontifícia Universidade Católica, Brazil  
<sup>2</sup>Prefeitura Municipal De Poços De Caldas, Brazil

Mental disorders are extremely prevalent in the population. In Brazil, Primary Health Care (PHC) is responsible for most cases. Objective: study the perception of physicians regarding Mental Health Care (MHC) from the perspective of Bioethics. This is a qualitative study designed as Descriptive-Exploratory in Poços de Caldas city. For the analysis, the Collective Subject Discourse technique was used. Twenty-one doctors working in PHC participated, representing 58.33% of the teams working in the municipality. 85% report that there are no protocols with therapeutic guidelines in their teams; 95% consider that it is the function of the PHC to pay attention to users in mental distress, but 60% of them do not consider themselves prepared to care for these users. The study also pointed out that stigma, prejudice, lack of training and medicalization are points of tension and harmful in professional performance in MHC. It also points out that PHC access and teamwork are sources of resilience. Encourage training, knowledge about available mental health protocols, and involve actors from various levels of MHC in the qualification process of care. Stimulating professional training, strengthening the matricial activity and continuing education are potent interventions to change this scenario, ensuring equity.

## Self-ownership and the Right to Decide over One's Body in Daniel Borrillo's Thought

Martí Colom Nicolau  
*University of Barcelona, Spain*

In recent years, matters in which people want to decide over their own body have increased greatly: euthanasia, final disposition of one's body, sexuality and gender, surrogacy, prostitution... Nevertheless, state interventions limiting individuals' liberty on behalf of dignity, humanity or inalienability of the human body are increasing too. The Argentine philosopher Daniel Borrillo has dealt with these much-debated issues in the book "Disposer de son corps: Un droit encore à conquérir". The aim of this lecture is to examine critically his stance on this subject, analyzing the two reasons that make it particularly interesting: first, the fact that, despite his commitment to the principle of self-ownership, he distances himself from libertarians and their classic defense of that principle, offering an alternative foundation of it; secondly, the fact that his explanation shows the weakness of axiologically neutral arguments when trying to justify restrictions on individual freedom, thereby compelling to look for new argumentative strategies in order to justify it.

## Moral Arguments on Treating for Research Purposes Microbiome Data of Patients Affected by Implant Infections

Noemi Condit

*University of Bologna - Alma Mater Studiorum, Italy*

Recent studies proved that microbiome samples and data are unique identifiers of the human host. This is especially true for microbiological samples of implant infections, because of the close connection among patients, implants, and microbes. Therefore, when used in research and stored in biobanks, these samples should be equated to biological samples, given their shared dual nature (both material and informational).

My presentation will focus on the moral advantages and disadvantages of two legal bases provided for by the GDPR which may be used to process microbiome data for research, namely - acquiring the consent of patients, thus ensuring the full exercise of patients' right to self-determination concerning provision of samples and feedbacks on results. However, the pool of patients affected by implant infections is limited, so lack of consents is problematic, and, even when provided, such consent may be withdrawn at any time, with serious consequences on the research project; or - resorting to the research exemption - this solution pursues mainly public interests, but the research itself may thus violate ethical principles and it may be questionable to provide feedbacks to patients.

Balancing the different moral arguments at stake helps assessing the preferable solution in conducting research on microbiological samples.

## Ethical Dilemmas Concerning Incidental or Secondary Genomic Findings

Vivian Coria<sup>1,2</sup>, Ronaldo Piber<sup>2</sup>, Lylyan Pimentel<sup>2</sup>, Michel Naslavsky<sup>2</sup>, Mayana Zatz<sup>2</sup>

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Among the scientific advances of recent decades, genomic medicine has established new strategies for health care, and is an intrinsic part of the methodologies advocated by Personalized Medicine. Given the increase in diagnostic and prognostic capabilities concomitant with cost reductions, genetic testing has become an increasingly frequent reality in the clinic, as well as becoming an essential tool for research, and even for commercial purposes such as ancestry. For medical application, findings of clinical relevance unrelated to the primary complaints investigated are treated as incidental or secondary findings, whose actionability for the tested individual or their family members is the subject of intense discussion and there are approaches recommended by different groups. In the application of tests in scientific research and in the relationship with the consumer, such discussion can reach other reflections, in particular about expectations and privacy. The aim of this paper is to compare the recommendations of different major centers around the world regarding the dilemma of reporting such findings and, in the future, based on these experiences, to elaborate the problem in view of the reality of the Brazilian population, in view of their heterogeneity, most frequent epidemiological profile of diseases and the possibilities of public management to subsidize tests by the public health system (SUS).

## The Double-Edged Sword: Ethical and Privacy Implications of FemTech

Bethany Corbin

USA

The digitization of the female body has slowly progressed under the guise of liberation and autonomy. Estimated to become a \$50 billion industry by 2025, the female technology industry ("FemTech") seeks to heighten awareness of women's health and enhance agency over women's bodies through the use of wearables, apps, and artificial intelligence. Reports have called FemTech revolutionary for women's health, with advocates seeking to expand FemTech beyond reproductive-based technology.

While FemTech glitters, its promises are not gold. Many FemTech devices operate in a regulatory void that permits them to collect and sell intimate and sensitive data for profit. The use of FemTech devices means women may unintentionally be losing control, privacy, and autonomy over their bodies. Further, this technology, riddled with assumptions of normalcy for the female body, results in the quantification of women and exclusion of large population subsets. The ethical and privacy implications of FemTech must be addressed during product development to ensure the FemTech industry does not become both a vehicle of change and a delayer of progress. This presentation fosters a dialogue on the ethical pitfalls of monetizing women's health, and proposes regulatory paradigm shifts to ensure health data is adequately valued and protected.

## Genetic Data: is There a Right to Oblivion?

Mónica Correia, Guilhermina Rego, Rui Nunes

*University of Porto, Portugal*

The technological developments of the past two decades made it possible to control and manipulate behaviors. New instruments and techniques such as robotics associated with artificial intelligence, the Internet of Things (which allows the communication of personal data for countless effects), or "data mining" (that permits patterns isolation), along with increased data storage and computing capacity, created a paradigm shift in almost every aspect of our daily lives. Ethical questions and complex dilemmas to deal with arise. One of the mechanisms that, to some extent, seeks to solve this problem emerged in Europe: the enshrining of the right to be forgotten, i.e. the data subject's right to delete personal data. This new law does not clearly define its limits and raises concerns worldwide, so it is important to discern whether it is ethically acceptable to delete sensitive data, primarily, genetic data.

Given the connection between Bioethics and Law, we look at the relationship between privacy and the protection of genetic data under the utmost formula of safeguard granted to its holder: the right to erase data. A discussion about the main ethical challenges posed by genetics in a reality of nearly absolute scientific and technological progress is proposed.



## Parents' Opinion on the Importance of Assent in Health Care

Hortense Cotrim<sup>1,2</sup>, Cristina Granja<sup>2</sup>, Ana Sofia Carvalho<sup>3</sup>, Carlos Cotrim<sup>2</sup>, Rui Martins<sup>4</sup>

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Regarding the importance of parents in child decision-making, Miller et al (2004) point out that there has been much discussion around children's rights to consent, with emphasis on the discussion on children's autonomy, which has relegated to second plan the important role of parents in this decision making. In this sense, Kodish (2003) points out that from an ethical standpoint in pediatrics, conceptualization has to be seen as a triangle, with the child in the top and the parents and the doctors at the bottom, working as a support.

Objective: To evaluate the opinion of parents about the importance of applying pediatric consent in health care. Descriptive and correlational study. Accidental sample consisting of 52 tutors, 40 females. Regarding academic qualifications, 38.5% have secondary education and 44.2% have a degree. 67.3% are married.

Results: We found that 96.2% of tutors consider that the request for informed consent was very important for the acceptance of the exercise echocardiogram by the minor. By the results we also concluded that there is no relationship between the tutors' opinion regarding the importance of the assent and their age, gender, education or marital status.

## Genetic Health Data and the Use of Consent Waivers... Where to from Here?

Margaret Craig

Dublin City University, Ireland

The force of the ethical imperative to obtain consent is of a powerful medico-ethical and legal nature, but changes in the way it is conceptualized are now evident. The benefits of using consent exemptions to facilitate genetic medicine which relies on the processing of secondary data where it is often impractical to gain consent are well known. However, there are growing fears around privacy and data protection in that genetic data can never truly be anonymized, which could erode trust in the research system and cause harm or stigma to participants, whose data is processed.

Regulators are challenged to police the new clinical research interface. The terrain is complicated and opting for a waiver does not mean that we settle for a diluted version of ethics. To date policies and guidelines to implement waivers are lacking. In medical ethics there is a tendency to focus on autonomy and individual considerations, which side-line competing and, in this case, more important communal objectives - that is the development of personalized medicine which relies on waivers to process data. Responsibilities must be clearly delineated so that secondary data can be processed in a principled and ethically sound manner that is respectful of persons otherwise we risk losing valuable progress in clinical research.

## The "Stop of Procedure" in Orthopaedic Surgery: Causes, Legal and Ethical Out-Come

Henry Coudane<sup>1</sup>, Orthorisq Orthorisq<sup>2</sup>, Eric Benfrech<sup>2</sup>, Christophe Le du<sup>2</sup>, Jacques Tabutin<sup>2</sup>,

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"Stop the procedure" is a term corresponding to the stop of the surgical procedure whereas this one has already started ie after the realization of the incision. It is different from the No Go which is applied from the moment a patient goes into the operating room up until the incision.

This complication is very rarely reported in the literature and the goals of this paper are to obtain a better understanding of the frequency, causes and consequences of the Stop of Procedure order to reduce the number of such severe incidents.

The frequency of the Stop of Procedure is a new complication described in orthopaedic surgery estimated at 0,5 to 1,0 % of the risk events. The problems bound to the management of orthopaedics devices is the first cause (36,7%) of Stop of Procedure and is confirmed by the investigations led with 1852 orthopaedics surgeons members of Orthorisq for whom the management of orthopaedics devices and prosthesis is the first cause of Stop of Procedure. Actually in France, the check-list cannot avoid a Stop of Procedure ; in its current shape is not adapted to the particular management of the devices in orthopaedic surgery because it does not include a control of the material in its reception.

Stop of procedure is a failure of the No Go procedure and establishes a rare but certain risk in the management of the patient which must be informed about it according to an ethical behavior.

## Blue Circle: Not be Afraid of his Death

Georges Cristini

Cercle Bleu, France

In accordance with a shy French society, the Law «Silence means consent» was passed in 1976, but was not systematically applied because, as a human being, the majority of the medical profession seeks the opinion of the family before any organ is taken.

How can this practice, which leaves out the responsibility of any citizen wishing to assert his decision, be remedied? A team of volunteers is investigating the matter.

10% write that they are for organ donation. 2% write they are against. The remaining, 88%, are those who decide nothing. The French are afraid of their death.

The Blue Circle, with the support of international member Authorities, Prof. Chris Barnard, Mgr D. Tutu, ... obtained the registration - at the French Data Protection Authority - of a third box to be ticked: "ABSTENTION", with delegation to the Medical Corps for decision.

This is the only "Register of the choice of the ends of life" in the world, that makes people responsible - without making them feel guilty - for the decisions they take for themselves. Isn't this fundamental in the case of a Pandemic!

Faced with this opportunity, the French State recognizes Blue Circle as a symbol of ethical and civic behavior, and subsidizes it for its register, stickers and road signs placed at the entrance of hundreds of Communes. When will it be distributed with any educational approach?

## Serious and Significant Genetic Condition, a Need for a Definition

Mair Crouch  
University of Glasgow, UK

Several areas of expansion in genomics indicate there is some urgency to develop a consensus in what constitutes a serious and significant genetic condition. Debates around the application of the CRISPR Cas-9 genome editing technique have been blurred by the potential application to either remove inherited genetic conditions or for enhancement. A definition would narrow the debate and make it more focused. Another area is the application of whole genome analysis such as the UK's 100,000 Genomes project, to uncover links between genetic variants and conditions. This raises issues of patient confidentiality, as a mutation detected in an individual may have health implications for other members of the family. If so, the patient may be required to agree to reveal this information to their relatives. Should they refuse, there are guidelines as to when a doctor can breach patient confidentiality and a definition could aid a defense for breaching that confidentiality but as highlighted in the UK case *ABC v St George's Healthcare NHS Foundation Trust* [2017], which goes to appeal at the High Court in London in November 2019, this area is complex. This presentation will include the impact of the decision whatever it is and will encourage debate.

## Mandatory or Voluntary Vaccination? Functioning and Effectiveness of the Legal Regulations Concerning Preventive Vaccination in Selected European Countries

Sebastian Czechowicz  
University of Lodz, Poland

The problem of the occurrence oscillates around the still living and often controversial matter of preventive vaccination. Protective vaccines are intended to have a preventive and antiepidemic effect. They are often perceived as a source of danger for human health and life. European countries approach the issue of preventive vaccination in different ways. In most countries` vaccinations are completely voluntary, in others there is an administrative obligation to vaccinate. There are also European countries where vaccination is a criminal offence. The number of legislative approaches in European countries coincides with the number of cases of individual infectious diseases, as well as with the different concepts of fundamental rights. Namely, should we protect the individual and his or her rights, or should we restrict the freedom of the individual to decide for himself or herself, in order to safeguard the rights of the entire collective in a given country? Or should we act post factum? These and many other questions raise the issue of preventive vaccination.

In the speech, the legislation of selected European countries representing different legislative approaches to the presented subject was presented in a comparative manner. The lecture was enriched with statistical data of the disease and the latest jurisprudence in the field of human rights and patient rights (among others: the right to information, the right to self-determination on the method of treatment).

## Herd Immunity and the Ethics of Vaccination

Pol Cuadros Aguilera  
University of Lleida, Spain

States have an obligation to protect the health of their citizens. In this sense, public health represents an important value, which must be addressed by public policies.

With respect to infectious diseases, states have an obligation to prevent their transmission. Therefore, the achievement of what is called "herd immunity" should be the main objective of policies to prevent infectious diseases.

In some countries, the Law gives the option of not getting vaccinated. In that case, where vaccination is voluntary, people who decided not to get vaccinated still have relatively high protection against infectious diseases.

This is because they live in a society where a sufficiently large portion of the population is vaccinated - the range is usually between 80% -95% depending on the type of disease, that is, they live in a "herd immunized society", and therefore they are "protected" as well.

But what would happen if too many people fail or decide not to get vaccinated and, consequently, seriously compromise herd immunity? What would the State do in such scenario, if it has the obligation to guarantee public health?

We will analyze some ethical ways to ensure that all healthy citizens are vaccinated and thus guarantee the herd immunity.

## Bioethics and Law / The Human Dignity in a Plural Society: Conditions and Challenges

Manuel da Frada  
University of Oporto, Portugal

The main topic is to discuss the conditions and challenges of the juridical concept of human dignity in view of the pluralistic value approaches to the matter in our democratic societies, where no authority can establish what is implied and in view that particularistic perspectives cannot be generalized and personal autonomy must remain having an important role.

The matter is central in bioethics and law, especially in the countries where human dignity is a concept of the legal framework and implies personal autonomy.

## Respect of Patient's Intimacy in Physiotherapeutic Practice: Fiction or Fact?

Emilia Dadura<sup>1</sup>, Agnieszka Wójcik<sup>1</sup>, Anna Ratajska<sup>2,3</sup>,  
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Physiotherapists, as public trust professionals, deal with their patients' intimacy on daily basis both at the physical level when conducting physical examination and touching their patient's body as well as the mental level while obtaining some confidential information concerning the treated person's life. Patient's intimacy becomes potentially vulnerable during treatment and for that reason physiotherapist's 'conduct' in this delicate and sensitive area is extremely important.

Respect of patient's intimacy might reflect physiotherapist's sensitivity to their patient's needs, express their care for them and may also help build a relationship based on trust. Thus, the main objective of the presented research was to verify how young physiotherapists deal with their patients' intimacy in their everyday practice and what their attitudes are.

A closer study of this issue will enable to verify ethical competence of young physiotherapists. It will also constitute a starting point for the evaluation of academic education effectiveness in this area. Hopefully the project outcomes, some of which will be discussed in the conference presentation, will become an important voice in the debate concerning ethical standards of the physiotherapist's profession which are currently being created in Poland.

The project was funded by the National Research Centre (2016/21/B/HS1/01824)

## Utilitarianism in Crisis

Samuel Dale

University of Toronto, Canada

The state of exigency and scarcity thrust on society by the emerging COVID-19 pandemic has produced novel interactions and tensions within normative ethical theory. One perennial battleground in Western ethics is occupied by the inherently incongruent frameworks of Utilitarianism, Deontology, and Autonomy. This theoretical tension, which I will articulate in this presentation, has manifested in our public health systems as healthcare providers struggle to fulfill their duty to provide the best possible care, and respect autonomy while saving the greatest number of patients. This is further compounded by the scarcity of critical medical supplies like personal protective equipment (PPE) and ventilators. In times like these, Utilitarianism often dominates decision-making from the physician level to the population level. While a maximizing principle may be ethically imperative in such circumstances, relying exclusively on consequentialist reasoning may produce unforeseen harms and moral injury if left unchecked by other ethical frameworks that maintain the dignity of human life, the equitable distribution of resources, and the autonomy of each patient. Although Utilitarianism is a useful ethical principle to employ when scarce life-sustaining resources must be responsibly allocated, it must be buttressed by the principles of deontology and autonomy to ensure proportionate, equitable decision-making.

## How well does Medical Education address Discrimination in Healthcare?

Alaa Dafallah

International Federation of Medical Students' Associations, Sudan

Although there have been widespread improvements in the delivery of health care over the last decade, social discrimination remains a significant contributor to the persistent negative health outcomes experienced by racial/ethnic minority populations.[1] IFMSA aimed to assess how medical education worldwide is addressing discrimination, particularly its implications in healthcare and whether it is adequately preparing the future health professionals to tackle different forms of discrimination against vulnerable groups.

In 2019, a global survey with 4 sections namely socio-demographic data; curriculum & assessment; learning environment; and student perceptions was launched. Qualitative data was also obtained through focused group discussions with students during the General Assemblies of IFMSA.

173 responses from more than 50 countries were obtained. In summary, 60% of responses reflected that topics regarding vulnerable groups and discrimination were not addressed in curricula particularly groups such as migrants and refugees, religious minorities and LGBTQIA groups. A significant trend was observed: learning environment was reported to be significantly less inclusive to the following groups: LGBTQIA+, religious minorities, refugees and migrants.

IFMSA reaffirms the need to ensure medical curriculum and learning environments are inclusive of knowledge about specific diseases and health issues impacting vulnerable groups.

## Seeking Help with Suicide: Addressing Our Human Need

Jim Damron

Atrium Health, USA

The Physician-Assisted Suicide movement continues to expand across the globe. States and countries continue to pass these acts to expand the options for those facing the end of life, primarily to ensure the preservation of their dignity. Numerous safeguards have been set in place to mitigate abuse, and research seems to support this desire. But are we missing a hidden motive?

Since its inception, supporters have changed the nomenclature of physician-assisted suicide to physician-assisted death and now to medical aid in dying. These semantic changes were put in place to decrease the emotional burden of the populace. But why do we feel the need to do so? Moreover, why do we feel the need to include others in this decision? Is it to ensure the efficacy of the medication or is there another more profound human need we are fulfilling?

In this presentation, we will examine other motivations for choosing this end-of-life option and consider the basic human need that it represents. If we are honest with ourselves and our desires, we will be better equipped to address the needs of patients and provide the best options to assist them at the end of life.

## Consent and Autonomous Vehicles

Eirini Darkadakis

National and Kapodistrian University of Athens, Greece

A.I. is offering humanity new ways to enhance a comfortable life environment by reducing workload both on a personal and business level. Complicated tasks are already being performed by machines and devices which incorporate A.I. operation to a greater or a lesser extent. For example, robotic vacuum cleaners, smart washing machines, A.I. assistants like "Alexa" etc. One of the key areas in everyday A.I. development these days is the autonomous vehicle. The main motive of this technological development is "advertised" to be the minimization of the death toll in the streets. But how does this revolutionary thought affect the free will of the agent? Is there going to be freedom of choice for action when a few years down the road all new cars will be fully autonomous? How do we know that A.I. will not take erroneous decisions due to programming faults? Who will take responsibility in case of accidents or even deaths in such cases, the driver, the programmer, the manufacturer, the state? Are autonomous vehicles better in these respects versus well educated drivers? This seems to be both a deontic from a Kantian perspective and a utilitarianism from the perspective of Bentham. This paper will present different aspects of such questions and the issues that occur focusing on the fundamental concepts of consent, autonomy of the agent, and free will, in comparison with a utilitarianism agency-based approach.

## A Qualitative Study on the Experiences of Antenatal Mothers Testing for HIV

Prema Dcunha

Father Muller Medical College, India

**Background:** HIV is a serious public health problem. An important component of decreasing the mother to child transfer is by counselling and voluntarily testing during pregnancy. Hence this test is offered to all antenatal attendees.

**Objective of The Study:** To study the experiences of antenatal mothers testing for HIV with regards to the counselling and voluntariness.

**Methodology Study Design:** Explorative qualitative study design

**Study Place:** PPTCT Centre at Father Muller Medical College Hospital, Mangalore

**Study Participants:** 15 antenatal mothers were enrolled by purposive sampling One PPTCT counsellor who is attached to the Centre and responsible for the counselling.

**Method:** In depth interviews were conducted for the mothers and counsellor using different sets of questions. The answers were analyzed for quality content.

**Results:** Antenatal mothers opined that the testing done was voluntary. They also learnt about HIV.

The counsellor found most difficult to counsel couples with discordant results.

## The Jam Session Format for the Clinical Ethical Training of Residents

Anna De Benedictis, Vittoradolfo Tambone

University of Rome, Italy

Medical training today is prompted by increasing pushes from a scientific, technical and economic point of view. They show themselves to be challenges regarding risks to lose sight of the human dimension of medicine, which in its grounded in an authentic interpersonal and integrated therapeutic relationship is essential for guaranteeing the ethical side of decision-making processes. In this respect, implementing an educational proposal aimed at acquiring specific bioethical skills could be a useful tool to support a better practice of medicine, especially for medical residents which are faced with the need to make good use of their background knowledge in daily clinical practice. Drawing upon interesting suggestions from the world of music, specifically from jazz, we designed a new format for the clinical ethical training of residents at University Campus Bio-Medico of Rome called Jam session to indicate the informal and not preordained nature of this approach. The Jam sessions coordinated by an expert ethicist are carried out as training opportunity for residents to present and discuss clinical cases drawn from their daily clinical practice by virtue of the ethical implications raised, as a starting point to take an active part in identifying shared and ethically grounded solutions.

## The Konomy: Autonomy which Takes Care of Relatives

Alain de Broca

University Jules Verne AMIENS, France

Who can take alone a severe health decision? In clinical situations, the patient will make a decision that will impact on his relatives. As examples, go back home with many technical treatments or take a decision on treatment withdrawals will lead to repercussions on all family members. It could be social repercussions or psychological impact (increase difficulties to enter the process of mourning). Our philosophical work has led us to propose the neologism "KONOMIE", a word extracted from Greek, from the two words "Koiné – nomos". This Konomie describes that ill people will make a decision which can make sense by everyone (consensus), and especially by their relatives. Distinct from both the former paternalistic model and the individualist autonomous model, Konomie requires that care-givers be ever more attentive to the patient to help him to discuss and explain his decision with relatives. This new way can reduce the number of misunderstandings between relatives and thus decrease the number of a family's dramatic situations. Konomie is really at the choir of the advance's directives compared to auto-determination which could be understood as a very individualist and dehumanizing choice.

## Ethics of First-in-human Transplantation Trials of Bioartificial Organs

Dide De Jongh, Emma Massey, Eline Bunnik  
Erasmus MC, University Medical Centre, Netherlands

Organ transplantation faces several limitations, including shortage of post-mortem donors and the need for post-transplant patients to use life-long immunosuppressive medication. In the last decade, the field of regenerative medicine has combined engineering and biological technologies in the attempt to (re)generate organs for transplantation. The European VANGUARD project aims to develop immune-protected bioartificial pancreases for transplantation into non-immunosuppressed type 1 diabetic patients. This project is creating a 'combination product' using cells and tissue from a variety of sources, including patient-derived cells, placentas and deceased donors. However, the clinical development of this combination product raises ethical questions, notably in first-in-human (FIH) clinical trials. As FIH trials of bioartificial organs are expected in the coming years, it is important to examine under what conditions bio-artificial organs can be safely transplanted in humans. In this presentation, we will discuss ethical conditions for clinical trials of bio-engineered organs, focusing inter alia on study design, subject selection, risk-benefit assessment, and informed consent. Drawing on existing literature on the ethics of clinical trials, regenerative medicine, stem cells, organoids, gene therapy, surgery, and transplantation, we will develop new ethical guidance for FIH transplantation trials of bioartificial organs.

## Comprehensive Decriminalization of Abortion: Legal Developments and Ethical Challenges

Fien De Meyer  
University of Antwerp, Belgium

Over the last decades, countries worldwide have liberalized access to abortion through partial decriminalization. Unsatisfied with the stigma still associated with abortion, some of these jurisdictions have recently adopted laws that completely decriminalize abortion in all stages of pregnancy and treat it as regular health care. These legal initiatives deny any role to criminal law when it comes to abortion regulation, in this way fundamentally moving abortion law and practice into a new direction. In this presentation, I will first discuss so-called 'comprehensive decriminalization of abortion' by studying the regulatory frameworks of Canada, New Zealand, and two Australian states. Next, I will examine the arguments for and against comprehensive decriminalization and explore studies of the impact of such a shift on the practice of abortion. Last, I will address both the legal and ethical challenges that may be raised by comprehensive decriminalization of late-term abortion. These insights will clarify the role that criminal restrictions and sanctions might play in abortion regulation.

## The Ethics of Tissue Engineering for Regenerative Purposes: A Systematic Review

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Tissue Engineering (TE), as a branch of Regenerative Medicine (RM), combines stem cells and biomaterial scaffolds to create living tissue constructs to restore injured organs. Examples include tissue engineered skin, 3D bioprinted bone and liver organoids for transplantation. The expectations of this rapidly evolving field are high, yet the ethical and societal implications remain to be mapped out. Therefore, we performed a systematic review of the ethical implications of the development and application of Tissue Engineering for regenerative purposes, as mentioned in the academic literature between 2008-2021. 200 relevant ethical and biomedical articles were included.

The review reveals that a significant body of literature exists on the ethical design of TE clinical trials, including participant selection and respect for tissue donors. Attention is drawn to issues raised by commercial incentives, unrealistic public expectations, and the apparent lack of suitable regulatory frameworks. Moreover, a range of societal implications of TE are pointed out, including high cost and challenges to fair distribution, and potential soft impacts on human identity, longevity, and enhancement. Overall, this comprehensive review paves the way for the responsible development of TE and RM and serves as a steppingstone for the ethical analysis of other emerging biomedical technologies.

## Fetal Viability as the Abortion Threshold in the Netherlands: An Ethical Analysis

Lien De Proost  
Erasmus MC, Netherlands

In this paper, we question the ethical legitimacy of fetal viability as the abortion threshold. We use the Netherlands as a case study. The Dutch law allows abortion until the fetus is viable. After fetal viability is reached, abortion is a crime against life. Viability is understood as that point in time at which a fetus can survive outside the woman's womb, with medical technological support if necessary. The gestational age at which viability occurs is determined by the Dutch Ministry based on the status quo in medical technological science. Currently, the limit of viability is set at 24 weeks and 0 days gestational age. The Dutch abortion law was drafted (a) to protect unborn human life and (b) to respect female autonomy. We will argue that viability as the abortion threshold is in fact incompatible with both principles. A viability-based threshold for abortion is incompatible with respect for the autonomy of the woman because it is a slippery slope towards an abortion ban. It is also incompatible with the protection of unborn human life because it does not protect the fetus against injustice and the form of harm that is severe pain and suffering. The underlying principles of the Dutch Abortion Law are violated by the realization of the law; the threshold for abortion in the Netherlands requires further reflection.



## Citizens' Perceptions on Ethical Issues in the Covid-19 Crisis: A Comparative Empirical Study

Kevin De Sabbata<sup>1</sup>, Rachel Brenner<sup>2</sup>, Annisa Ika Putri<sup>3</sup>, Maurizio Ballistreri<sup>4</sup>, Welcome Wami<sup>5</sup>, Pim Klaassen<sup>2</sup>

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COVID-19 has confronted governments, health authorities and professionals with difficult choices impacting the fundamental rights of citizens. For example, freedom of movement had to be restricted in order to limit the virus circulation and in some countries the overburdening of hospitals required to establish controversial triage protocols, giving priority to certain categories of individuals over others in access to life-saving treatment. Remarkably, such impactful decisions tend to be taken following a technocratic logic and hence are seldom publicly discussed. Therefore, we still have a poor understanding of what the different members of society think about these controversial choices and how they form their opinion in these circumstances. In order to fill this gap, we have conducted a mixed method study consisting of interviews and a questionnaire distributed in four countries: The Netherlands, Italy, Indonesia and Kenya. The aim of the research is to highlight the main opinion trends regarding controversial ethical choices in the COVID-19 crisis and study how a different social, cultural, economic, political and historical background leads to a different view of such decisions.

## Artificial Discrimination: How Predictive Machine Learning Algorithms Bring About Greater Potential for Mental Health Discrimination

Valerie De Wandel  
Saint Louis University, USA

While Google's deep learning system application is a more popular example of predictive algorithmic decision making, another was brought to light in March 2017 when Facebook launched a project to try and prevent suicide through AI. To differentiate, however, Google's deep learning system is directly connected through health care, while Facebook's data collection method is not held to the same privacy standard as healthcare providers. Thus, although the algorithm technically collects mental "health" information, the regulations are not held to the same standards. This presents a concern for potential discrimination.

This loophole will be depicted through a case study of a student who was denied employment based on decisions by predictive algorithms. Furthermore, this paper will describe how such discrimination could bypass various regulations including the Health Insurance Portability and Accountability Act (HIPAA), the Americans with Disabilities Act (ADA), and the Genetic Information Nondiscrimination Act (GINA). Subsequently, this paper will analyze recommendations to amend the ADA, along with amending HIPAA. Lastly, this paper will present a call for more attention surrounding AI in relation to all current global regulations, in addition to recognizing that AI does lack some important characteristics that can only be obtained with human communication.

## Bioethical Dilemmas Associated with Autism Spectrum Disorders People's Care

Daniel de Sousa Filho  
Faculdade IPEMED de Ciências Médicas, Brazil

Autism is a concept surrounded by controversies since its description in 1943. Currently included among Autistic Spectrum Disorders (ASD), there are still heated debates among health professionals and recently, autism has started to be the focus of research among bioethicists.

In this context, approaches, both for diagnosis and treatment, usually not based on evidence and associated with several risks. Besides, many of them are associated with adverse events, including reports of deaths, and basic human rights violation, since many alternative practices are conducted, without any scientific basis, despite guidelines and doctors and other experts' alerts.

Furthermore, it is not uncommon for people with ASD to be deprived of their basic rights, such as access to vaccination, adequate food and specialized health.

Still, a lot of people with severe ASD are deprived of freedom, living in subhuman conditions, or in private prison, without any basic hygiene and health care. All of these involve important ethical issues that are little discussed, a fact evidenced by the scarce number of publications on the ASD's ethical issues.

Thus, the objective of this work is to review the literature and describe non-evidence-based interventions in the treatment of people with ASD and their bioethical implications.

## Ethno-Religious Assumptions in the Formation of Bioethical Epistemological Framework

Alan Delotavo  
Societal Rebranding Ltd, UK

In the age of multiculturalism and political correctness, bioethics is polarized by religion, politics, and media hype. The polarization is further compounded by the conflicting diversity of embedded ethno-sectarian religious beliefs upon which several societies, or groups within a society, based their dogged ethics.

An example is while flu vaccination is accepted by many American Christians, the fundamentalists don't (ref CNN on February 7, 2018) on the ground that it's Jesus that protects everyone from flu. Another example is, while surrogate motherhood is not permitted among Sunni Muslims, it is allowed among Shiites although for legal couples only.

The purpose of this paper is not to pit religion against science but to point out the nature and function of religious beliefs so bioethicists will have a deeper understanding of religion and its implications for the formation of bioethical epistemological frameworks. And use this understanding to educate others. The eye-opening core assumptions of religious beliefs that significantly impact bioethics will highlight this presentation.

### **Preimplantation Tests in the Light of the ECtHR's Judgment Costa and Pavan v. Italy: Between Moral and Pragmatic Issues of the Desire to Conceive a Healthy Child**

Adriana Denys-Starzec  
University of Warsaw, Poland

The application of preimplantation tests, giving the possibility to evaluate and select embryos before implantation, is undoubtedly desirable in the event of the risk of transmission of a serious genetic disease. On the other hand, however, there is a risk that this complicated procedure may be used for purposes other than those originally envisaged, i.e. sex selection or creation of a child with specific features ("designer baby", "saviour sibling"). The lecture will present some moral arguments (such as the principle of harmlessness, prohibition of suffering, wrongful life argument) in favour of negative selection ("screening out") due to genetic defects and theses opposing this attitude, including the argument on the return to eugenic practices and the rule of non-discrimination regarding persons with disabilities. These considerations will form the background for the analysis of the ECtHR's judgment Costa and Pavan v. Italy on the access of couples with a genetic defect to preimplantation diagnostics. In this judgment, the ECtHR acknowledged that the desire to conceive a child free from genetic defects is part of the right to respect for private and family life, guaranteed by Article 8 ECHR. The analysis will also provide an insight into pragmatic arguments allowing for preimplantation tests.

### **Veterinarian Moral Distress: Ethical and Legal Issues of Euthanasia**

Annalisa Di Mauro, Carmine Guadagno  
Animal Law Italia, Italy

Animals are sentient beings, and companion animals are ever more becoming considered as members of the family. Nevertheless, the legal status of animals in Italy and in other countries decrees that they are still "res", property.

On the other hand, we have witnessed the increasing number of specialty veterinary practitioners and to the development of new diagnostic and treatment modalities (dialysis, chemotherapy, complex surgeries, immunotherapy), and also of food and drugs, for large and different approaches to animal diseases.

Always more frequently the animal owners want to continuing treatments regardless the animal suffering and animal's quality of life. Selfish desires and wishful thinking may overcome objectivity.

When veterinarians start the relationship with clients, they should introduce to them considerations about quality of life. Even though the client knows the animal and what makes it feel good, the veterinarian knows the consequence of a dysthanasia.

Veterinarians are beset with law and conscience. They are moral stressed by frequent requests of convenience euthanasia (that is not allowed in Italy and in other countries), but they're also stressed when they can't end the suffering, by providing peaceful and painless death, to their patients.

### **Ethical Issues and Moral Sensitivity Among Indian Physiotherapist: A Descriptive Study**

Poovishnu Devi<sup>1</sup>, Jagatheesan Alagesan<sup>2</sup>  
<sup>1</sup>Krishna Institute of Medical Sciences, India  
<sup>2</sup>Saveetha College of Physiotherapy, India

The aim of the study was to identify and describe ethical issues encountered by Indian physiotherapists in daily clinical context and moral sensitivity in ethical situations which enhance physiotherapist's ethical understanding and to improve the ethical quality of physiotherapy. A questionnaire-based survey was constructed to identify ethical problems, and moral sensitivity was measured by Moral Sensitivity revised version Questionnaire. The study was a descriptive and co relational study using cross-sectional questionnaire. A total of 378 physiotherapists working in both outpatient and inpatient physiotherapy setting were included. Questionnaires were forwarded using Google forms software. A remainder was sent after 3 days and fully completed 320 responses were received. Longer working experience increases the self-estimated ability to sense when a patient is not receiving good care (p-value = 0.022). Moreover, ageing seems to increase the feeling of being able to talk about difficult things with the patient (p-value 0. = 21). Results of the study emphasized that most of the physiotherapists encounter problems related to everyday ethics, mainly concerning the lack of resources, discrimination due to individual differences and unethical conduct of other health-care professionals.

### **Survey on Habits Related to Alcohol Consumption in University Students: Observations and Future Perspectives**

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**Introduction:** The use of alcohol is common among university students as it is often part of the process of social regulatory development, but its use can also cause serious consequences: mortality, morbidity and disability. The aim of this survey is to research the situations in which students consume alcohol and know their lifestyles related to alcohol consumption.

**Materials and Methods:** 194 university students of Psychology participated in the survey from February to December 2018. Alcohol consumption was examined through the Alcohol Use Disorders Identification Test (AUDIT) and, to test characteristics of the ways and places of consumption was built a multiple-choice questionnaire.

**Results:** The completed questionnaires were 194 (88 % of the total distributed). Consumes wine and beer once a week on average around 32% of the sample and 4% consume alcohol daily. AUDIT highlights that 59% of students present alcohol-related problems and 41% are identified as consumers at risk, with a prevalence for males (P 0.03).

**Discussion:** It emerged that all students have a harmful or risky alcohol consumption, mainly occurs in friends' homes, confirming how alcohol consumption appears to be a prerequisite to socialize. Prevention strategies appear essential in this age group, which is a risk category.



## Ethical Issues in the Management of Opioid-dependent Patients: Substitution or Withdrawal

Paolo Di Patrizio, Christophe Clesse, Jane-Laure Danan,  
Henry Coudane, Martine Batt, Gisèle Kanny  
*University of Lorraine, France*

In the last 30 years, both therapeutic and illicit opioid use have increased. The total number of opioid prescriptions dispensed from U.S. outpatient retail pharmacies is estimated at about 260 million in 2009. Around 1.6% of the population aged 12 or older in the United States are current nonmedical users of prescription opioids.

In France, in 2015, the national illicit drug market is assessed at €2.3 billion.

Through our work, we try to review the doctors' ethical questions when they prescribe opioid therapeutics or treat opioid-dependent patients. Within the context of the emergence of new users of non-prescribers' opioid treatments, the following ethical questions arise:

-how to prevent the risk of abuse when a opioid's prescription is required  
-what is the best option when a doctor had to care opioid-dependent patients: substitution or withdrawal?

To answer these questions, we should take into account different patient's factors such as age, ongoing pregnancy, social context, relapse, risk of overdose, personality profile, etc.

In case of opioid prescription or substitution to illicit use, each prescriber should be aware of ethical issues.

## "Universal" Healthcare? Disparities in Care of Indigenous Canadians

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*Laurentian University / Northern College of Applied Arts  
and Technology, Canada*

Canadians boast about Canada's universal healthcare system as a topic of national pride. However, what is ignored by many is that indigenous Canadians experience poorer health outcomes and inferior life expectancy compared to the rest of Canada. Indigenous individuals are more likely to die young from violence or trauma and infant mortality rates are double non-indigenous individuals in multiple provinces. Chronic diseases also disproportionately affect Indigenous Canadians, the most significant being diabetes. When questioning a system that was created to provide equitable care for all citizens, why does such a large disparity exist? What changes can be made to better care for all Canadians? Some of the most damaging effects of colonization surround the residential school system. Indigenous children were taken from their homes by coercion or force to attend church run schools. Unfortunately, most practicing clinicians have no formal education about the intergenerational impact of this trauma or its role in institutionalized racism. This lack of knowledge allows ongoing racism and prejudice to run unchecked. This presentation will seek to showcase the ethical responsibilities of medical and nursing schools to include comprehensive teachings around indigenous history and values as a way of aiding future practitioners in eliminating this disparity.

## Law & Literature and Bioethics

Caio Dib<sup>1,2</sup>

<sup>1</sup>*University of São Paulo, Brazil*

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Since its inception, bioethics has concerned itself with the dialogue between different systems of beliefs and knowledge. After all, bringing science and humanities together is an essential part of Van Potter's project for bioethics as a science of survival, a "knowledge of how to use knowledge" (Potter, 1971). Bioethics has also deemed important the inclusion of different worldviews in the fora and the development of a reasonable response to pluralism, being aware of the diversity of populations (Montgomery, 2016). However, the discipline has struggled with developing a theoretical framework that helps to bridge its normative and descriptive dimensions, especially when it comes to properly clarifying the cultural roots of bioethically-relevant beliefs. Beyond its theoretical relevance, knowing the narratives that justify the positions of individuals and communities helps to find a middle ground and better answers in pluralistic societies. By recurring to legal scholarship in law and humanities developed as an effort to better describe the symbiotic interaction of norm and narrative – namely, law and literature – the discipline of bioethics may improve its understanding of the meanings that underly cultural aspects of bioethical dilemmas, refine its approach to (bio)ethical pluralism, and provide new solutions for challenges of present and future.

## Bioethics and Medical Confidentiality Protection in Disaster Victim Treatments by Foreign Medical Personnel in Indonesia Reviewed from the Utilitarianism and Positivism Legal Theory

Djarot Dimas Achmad Andaru  
*University of Indonesia, Indonesia*

The dilemma between live saving treatment in emergency response and protecting the patient privacy rights as well as keeping bioethics on the line are a significant challenge for the field medical personnel in playing their role as a lifesaver and competence yet professional personnel, especially during crises. Foreign medical aid personals are the ones who are likely to face the dilemma since they are not familiar with the local ethics. Which resulted in the closure of foreign aid access. It has been a long debate on how legal norms should govern in emergencies situation example in saving mass disaster victims. Whether it should maintain the utilization of legal norms for the greater interest of the people by compromising the standard of bioethics and patient's protection. Or prioritize the enactment of bioethical and medical confidentiality standards. In this scenario, sometimes bioethics and patient's right are victimized and neglected to be bargained with the common interest in treating and saving disaster victims. Under the utilitarian legal theory, such an act is recognizable as long as it focuses on the utilization of law for the highest benefit or interest of humankind. It directly contradicts with positivism and natural legal theory which emphasizes the moral value.

### **Plea for the End of a Name without Respect. A Proposal from an Association of Mental Health Professionals in Cameroon**

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Emmanuel Richard Dipoko Dibotto, Effa Pierre,  
Bengono – Toure Naoban Geneviève,  
Zoe Obianga Jean, Effa ateba Victor  
Yaoundé CERB Unit, Cameroon

The highest concerns of Bioethics are the protection of Life and respect of human dignity. It is the initial concept of Bioethics namely a perception of biosphere, where man interacts with the environment. According to the African paradigm of bioethics, man is called to live in a community where everyone feels protected and respected.

Healthy Environment for Living People (HELP) has realized that people who suffer from disabilities carry the name of this infirmity. even healthcare professionals demonstrate this irreverent behavior toward the patients they care for. They use nickname to call patients. So, they are reduced to being perceived through what can provoke their malaise. This attitude is contemptuous and discriminatory. nor does it promote the respect of this person, or even his or her integration into the host community.

For an effective respect of these people, HELP suggests that the offensive name "DISABLED" should be replaced by "PERSON LIVING WITH A DISABILITY".

Our advocacy is part of the implementation of the African paradigm of bioethics in grassroots communities.

### **Informed Consent to the Medical Treatment of Minors**

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Tomáš Doležal  
*Institute of State and Law of Academy of Sciences, Czech Republic*

The lecture is dealing with the problem of the competence for decision-making by minors and is focusing on the examination of the laws concerning medical treatment of minors, that is, persons under the age of 18. The first part of the lecture discusses whether persons under the age of 18 may be regarded as being capable of consenting to medical treatment and the problem of maturity. Further this lecture brings a short comparative overview of the laws concerning medical treatment of minors in different countries. And finally, the last part analyzes the capacity to consent of the minors under the current Czech laws.

### **End-of-life Decisions in Czech Republic**

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Adam Doležal  
*Institute of State and Law of the Czech Academy of Sciences,  
Czech Republic*

This lecture is concentrated on the topic of end-of-life decisions in Czech Republic. There is a huge topic between doctors, lawyers, and ethicists about proposal of the Euthanasia Act, which will be soon negotiated in Czech Parliament. Therefore one of the topics of this presentation would be the wording of this act and some problematic aspects of it. Another important issues at the end-of-life discussion should be also critical decisions like withdrawing and withholding of life-sustaining treatment and palliative sedation. They are maybe even more important but their legal background in Czech Republic is critically insufficient. Current legal conditions are in direct contradiction with judicial opinions of European Court of Human Rights, especially legal opinion expressed in *Lambert and others v France* and *Glass v. the United Kingdom*. In this lecture there will be presented this insufficiency of Czech legal order and compare it with ECHR case law.

### **Macedonian Case of Bioethics: History & Future**

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Dejan Donev  
*University "St's. Cyril and Methodius", Republic of North Macedonia*

While the world is fighting with the climate changes and other problems, at the very same time, this same world is doing its best for including the bioethics and bioethical education in becoming active parts of saving lives and living. Unlike many neighboring countries on the Balkans, in N. Macedonia one doesn't talk about bioethics as a developing discipline, which is a normal fact or part of scientific activities and research, or even less does one talk about bioethics as something that is a systematic part of education, including bioethical education, up 'till the last few years. So, what happens in N. Macedonia with the idea and practice of bioethics in the moment? Does it have any kind of trace in term of history of the bioethical efforts? Even more, what kind of future does it have for the next generations?

## Peculiarities of Teaching Bioethics in the Russian Medical University

Alena Donika  
Volgograd State Medical University, Russia

The problem of the demand for bioethical education for medical students is connected with the negative tendency to curriculum reduction of humanitarian disciplines in Russia. This point of view appeals to the strengthening of the professional component that determines the profile competencies of a specialist. In particular, it is proposed to reduce the teaching time for bioethics in medical higher schools for its use in teaching operational techniques, so-called practical skills. According to the results of sociological research of students of medical higher school (N = 92, average age  $19,2 \pm 1,01$  years) 54.3% of respondents believe that a 15-year-old patient cannot give consent to cosmetic surgery alone, 27.5% of students found it difficult to answer, just doubting the possibility to make adequate decision at the age of 15. Students are shown the complexity of an ethical solution, seemingly formally resolved by the rules of the law of the problem. This problem raises a number of other ethical dilemmas, initiating students' interest in the ethical side of professional activity. Despite possible discrepancies in the legal norms of national laws, cultural, confessional or atheistic peculiarities of countries, the ethical problems of professional activity are of a general nature.

## "If you're Gonna do it, do it Right-Right": An Argument for Beneficence in Neurocorrection

Emma Dore-Horgan  
University of Oxford, UK

Neurointerventions – interventions exerting direct physical, chemical or biological effects on the brain – are sometimes administered to criminal offenders to reduce their recidivism risk and promote their rehabilitation. Ethical debate on such 'neurocorrectives' has focused on the issue of consent, with some defending a consent requirement in their use and others rejecting this. In this paper, I remain neutral on the consent issue and instead defend a beneficence requirement. I argue we ought to require, as part of our ethics codes for neurocorrection and as a matter of law, that these interventions promise to confer a greater balance of benefit over harm upon their recipients.

My discussion is as follows. Section 1 makes a consistency point with healthcare. I argue consistency seems to demand the bioethical principle of beneficence extend to the case of neurocorrectives, given these interventions must be prescribed and/or dispensed by a healthcare professional. Section 2 develops this consistency point by contending arguments which support an 'almost always decisive' legal duty of beneficence in healthcare are also justified in the neurocorrective context. Specifically, I contend beneficence is justified to maintain trust in medicine and to safeguard against abuse. Section 3 addresses reasons for thinking neurocorrection might be importantly different from healthcare such that a beneficence requirement need not apply. Section 4 concludes.

## Value of Closeness in the Context of Relations Between Physician, Patient and Close Relatives

Marlena Drapalska-Grochowicz  
University of Silesia, Poland

As a rule, a doctor and a patient have a specific "bond" based on trust and care. Sometimes, treatment and illness influence and involve close relatives. What relationship is formed between the doctor and patient's relatives? How the value of their presence should be treated in this context – as something positive or as obstacle for patient and doctor? What relatives should know about our health and do they have any title to that? Do we „belong” to our relatives in some extent? How should physician treat close relatives and recognize them?

In the speech based on the analysis of Polish and Spanish legal solutions, the impact of "close relatives" on the treatment process will be considered – who is "close relative" to the patient, what is the information scope for "close", the participation of close relatives in treatment, on the other hand - the issue of medical confidentiality and its limits, the scope of information that the doctor has about the patient, the doctor's attitude towards the patient and close relatives. In the presentation author try to explain broader issue – where are the limits of human health and what of intimacy?

## Cinemeducation: A Comprehensive Approach to Bioethics Education in Health Sciences Curricula

Derek D'Souza<sup>1,2</sup>

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Alexander, Hall, and Pettis (1994) have mentioned the use of cinema in teaching psychosocial aspects in medicine and termed it as "Cinemeducation". It is well established that adult learners learn best via audio-visual stimulation and it has been proven as one of the most reliable methodologies of contemporary teaching-learning practices. It is also in tune with the principles of andragogy where the adult learner is directed towards self-actualization, gaining experience, and problem-solving. Short video clips either from movies, television shows or even specifically created content can be used to stimulate enriching discussions with medical learners. These can be used in the teaching of bioethics, especially with undergraduate and post-graduate health sciences students who often have limited personal life experience. They are a valuable tool for discussion and to motivate further self-study and learning. Short clips from movies are an effective way to initiate a discussion with students in personal and professional development modules as well. By using the dynamic tools of self-reflection on the actions of the characters on screen, healthcare students can grasp the concepts of sympathy, empathy, caring and further use these as motivation for real-life choices, as competent and caring healthcare professionals.

## **Regulating Genetic Research and Applications: The Role of International Soft Law and Chinese Practice**

Li Du  
*University of Macau, Macau China*

The continuous advancement of genetic research and clinical applications raises legal and ethical challenges to not only domestic regulatory agencies but also international communities. Existing literature has shown that soft law, i.e., guidelines, codes of conduct, etc., has its own advantages in regulating fast-changing technologies such as genetic technologies. Particularly, compared with traditional treaty-based approaches, international soft law was considered more efficient to reach optimal harmonization measures among countries for dealing with legal and ethical issues associated with emerging technologies. In the field of genetic research and applications, international organizations have initiated to develop various declarations, guidelines, best practices, etc., to harmonize the regulatory approaches governing research and development of genetic technologies. However, few studies have explored the scope and content of these soft laws and, in particular, what the role of China, an important player in the field, has played in the development of international soft laws on genetic research. This study will review the existing international soft laws on genetic research and applications. It will then explore how China has been involved in the development of these soft laws and the impacts of international soft law on China's domestic regulatory framework on genetic research and applications.

## **Obstetric Violence and the Birth Experience: The Role of Informed Consent**

Jennifer Dunatov  
*Mount St. Mary's University, USA*

Public awareness of the global obstetric violence epidemic has grown substantially in recent years, though bioethical literature addressing the topic is scant. Obstetric violence refers to the disempowerment, disrespect and/or abuse women might encounter in their clinical birthing experiences. The World Health Organization currently identifies "prevention and elimination of disrespect and abuse during childbirth" as an area on which governments ought to focus increased attention. Research has shown that in the United States women often cite a lack of informed consent as the primary contributor to their moral trauma resulting from obstetric violence. This moral trauma has the potential to affect their own postpartum health and potentially the health of their babies. This presentation will examine the role and complexities of informed consent in the clinical birth experience through the lens of relational ethics. I argue that the centrality of relationship within the moral community (relationship between practitioner and mother, between mother and baby, between family and institution) is paramount in the quest to maximize the dignity of the birthing patient. In focusing on the reduction of obstetrical violence and the importance of relationship in the informed consent process, facilities can work to empower women and providers to be agents of change in the birth experience.

## **Predictive Genetic Testing in Huntington Disease: Ethical Dilemmas and Patient's Right to Information**

Raluca Dumache, Maria Puiu, Alexandra Enache,  
Alexandra Mihailescu  
*Victor Babes University of Medicine and Pharmacy Timisoara, Romania*

In Huntington disease, predictive genetic testing rises ethical issues in social, legal, economical, personal and familial aspects. In the age of advanced genetic testing, the ethical question which rises is how the predictive genetic testing can affect a person, his or her family and relatives, life choices and future. Another ethical question that should be addressed to medical geneticists is: should an incurable hereditary disease be diagnosed before the symptom's onset? If predictive genetic testing is available, what ethical justification can be to communicate the information to the concerned person? Genetic testing allows the identification of individuals who are carriers of some mutations in their genes, these mutations being the cause of some genetic disorders. Predictive genetic testing leads to genetic discrimination, towards the individual in regard to rights, privileges and opportunities, based only on genetic information and medical history.

We have in Romania some limitations regarding this type of predictive tests, because we don't have interdisciplinary teams to coordinate the management of these cases. Another disadvantage regards the ethical problems of information and patient consent. regarding genetic diseases leads to discriminatory practices. All these problems need to be urgently solved and implemented in Romania, due to the special aspects belonging to them, especially in patients with Huntington disease.

## **Communication and Resolution Programs (CRPs): A Growing International Movement in Healthcare Systems**

Aaliyah Eaves  
*Dinsmore & Shohl LLP, USA*

Market pressure, physician burnout and demands for safer care drive the transformation towards what some call Health 3.0. Proponents of this new paradigm urge putting relationships at the center of the healthcare enterprise to maximize the good for all stakeholders. One example is a shift away from highly adversarial adverse event investigation and claim resolution processes that destroy trust and discourage transparency. Communication and Resolution Programs (CRPs) are a burgeoning international movement in healthcare systems that utilize various forms of conflict resolution to address patient harm and repair fractured stakeholder relationships. Although conceptually simple, implementation is often arduous, with the ethical maturity of the organization factoring considerably into its success and sustainability. Skeptics argue these programs are a selective risk-mitigation tactic to prevent patients and healthcare providers from receiving due process, often pointing to the fact many CRPs are aligned under legal or claims management departments. In response, I advocate for merging clinical ethics programs with CRPs in an integrated ethics management strategy in order to produce greater efficiency, ROI, stakeholder trust and high reliability for healthcare systems.

## The Early Life and The Laws of Bioethics

Victor Joseph Steve Effa Ateba  
COPAB/CERB, Cameroon

Bioethics is a multidisciplinary science that studies problems related to research in biology, medicine, genetics, among others, and their applications. Bioethics ensures respect for the human being. Bioethics addresses such issues as: early life, abortion, assisted procreation, contraception, etc.

In the World, Africa is the most restrictive region in terms of the right to abortion. The illegality of abortion is the rule with a few exceptions (South Africa). The technique and the integration of women at work produce socio-cultural changes that bring out new choices for the couple in terms of fertility. How to take advantage of technological development while preserving our humanity?

The personal destiny of man leads him to freedom as a subject. This extends to society, thanks to the generation of children. From the current and almost total trust of many parts of the world to all these techniques such as artificial reproduction and abortion, there is a risk that man will leave his destiny to become an object of his own reality.

## Informed Consent or Scare Tactic: Ethical Implications, Challenges and Solutions for Discussion of Pediatric Anesthesia-induced Neurotoxicity Warnings

Rhashedah Ekeoduru  
The University of Texas Health Science Center at Houston, USA

Imagine you are a parent who has just been informed that your young child requires surgery. You are presented with information about the risks and benefits of surgery, including the risk of long-term complications from anesthesia that can cause learning disabilities and behavioral abnormalities. It would be understandable for you to be anxious, experience stress and possibly have difficulty providing consent for the procedure. Are we inflicting psychological harm on parents in an effort to explain a theoretical risk? How many parents are too frightened to proceed with necessary procedures after receiving confusing, yet troubling information?

The focus of this talk is to discuss how physicians and healthcare providers should interpret the FDA safety warning about anesthesia-induced neurotoxicity in pediatric patients following repeated or lengthy exposure to anesthesia. How should physicians communicate anesthetic risk when conclusive research in humans is pending?

I will explore the ethical implications of providing limited, confounding information to parents and advocate for creating guidelines to properly counsel parents using meta-communication approach. I will also provide suggestions to reduce anesthetic exposure, thus mitigating risk which include limiting learner influence, patient advocacy, creating a systematic framework for disclosure and improving cross-specialty communication.

## AI in Healthcare; An Ethical Analysis of the New Paradigm

Perihan Elif Ekmekci, Banu Buruk  
TOBB ETU School of Medicine, Turkey

AI technology is progressing rapidly in healthcare. This progress implies a paradigm shift that will have consequences on one of the major components of medical practice, interaction and consultation.

Physicians, by communicating with each other, go through their decision-making algorithms to detect the righteousness of the evidence data, the consistency of the thinking process and the validity of inferences.

However, this interaction process is not possible between AI systems and physicians, since AI uses deep learning to develop its self-generated algorithm, called "the black box"; which is even hidden to its developers. For example, AI radiologists by studying billions of images develop a decision-making algorithm to diagnose a cancerous image. However, they neither have the capacity to explain their decision process nor discuss other possible ways of thinking with their human counterparts. This would create a new paradigm that would limit the physician's effectivity and leader position in clinical settings. Moreover, the lack of interaction and consultation would hamper the motive to make research to discover the unknown and creativity in medicine.

It is important to realize and discuss ethical and medical implications of this paradigm shift before it happens; so that if risks outweigh benefits a different course would be taken.

## Humanizing AI in Healthcare

Bogi Eliassen  
Copenhagen Institute for Futures Studies, Denmark

With the huge leap forward in new technology and data there is a need to focus on framing the cornerstones for future health models where AI necessarily will be a core component. Based on decades of work with genomics and data this presentation will look at our opportunities in improving healthcare and building more sustainable health models and at the same time emphasizing on the enabling role of AI and challenges that arises with its application. The presentation is centered around Copenhagen Institute for Futures Studies models, the Humanome, and the Sustainable Health Model and what are the possible scenarios for AI in healthcare.



## Ethical Challenges Encountered by Health Care Professionals Participating in Medical Humanitarian Aid Work: Summary of 25 Years of Experience of International "Save a Child's Heart" Activity

Anat Engel<sup>1,2</sup>, Lior Sasson<sup>1,2</sup>, Simon Fisher<sup>3</sup>

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<sup>3</sup>Save a Child's Heart Foundation, Israel

**Background:** A unique international humanitarian medical aid work is taking place at the Wolfson Medical Center (WMC) in Israel, for 25 years. This work includes pediatric cardiac surgeries and catheterizations, performed in above 5000 children with heart defects from above 65 countries over the world. The activity is done in the countries of origin of the children by Wolfson's pediatric cardiac medical staff going on humanitarian delegations, and in WMC itself. This activity is supported and funded by "Save a Child's Heart" (SACH) foundation. Ethical challenges are constantly encountered by health care professionals (HCPs) participating in this medical humanitarian aid work.

**Objectives:** Learning the major themes of the ethical challenges expatriate HCPs experience while providing care on SACH missions abroad.

**Methods:** Collecting data and narratives from past recorded summary discussions and interviews with the HCPs before and after SACH missions. Results: 50 WMC-SACH HCP's were involved over 25 years in expressing the ethical challenges they faced through SACH activity. We divided the challenges expressed into several major themes.

**Discussion:** Saving children's lives and making the world a better place are the noble humanitarian objectives of SACH HCPs activity. Several major themes of ethical challenges rose up during 25 years of SACH's activity. Addressing these ethical challenges is an ongoing objective for improving the next delegations and avoiding burnout of the medical team.

## Road Remains: Bioethical Valuations in Death

Flávio Rodrigo Araújo Fabres<sup>1,2</sup>

<sup>1</sup>Federal University of Campina Grande, Brazil

<sup>2</sup>Federal University of Paraíba, Brazil

**Introduction:** Multidisciplinary, Bioethics presents several observation niches of human and non-human actions. For Bioethics, life, regardless of the species considered, represents unique valuation in the complexity of the biosphere and every living being has the right to be respected by the other components of the web of life. Auto accidents involving humans have a greater bioethical impact compared to accidents with nonhuman animals and such difference can have a negative impact on society.

**Objective:** To evaluate if, in the bioethical context, some lives have value gradation.

**Methodology:** Literature review and critical reading, searching the keywords "life", "value of life" and "bioethics" in PubMed, Scopus, Web of Science and specialized textbooks.

**Result and discussion:** There are four ethical streams confirming the existence of "intrinsic value" in elements of decreasing biological complexification: anthropic ethics, animal ethics, biocentric ethics, and ecocentric ethics. The human being has an "intrinsic value" greater than the other living components in the biosphere and the man acquires special status before the living beings.

**Conclusion:** When relativization in the valuation of life becomes commonplace, life as a whole loses its appreciation globally.

## Mehusgan NGO: A Revolution in Community Standards for Social Immunity and Public Health Advocacy

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<sup>1</sup>Maccabi Healthcare Services, Israel

<sup>2</sup>Sheba Medical Center, Israel

**Background:** Despite large consensus that vaccinations are of the most important inventions of preventative medicine, anti-vax movements are growing, causing the return of preventable diseases. Measles being the most contagious.

During last year Israel had an outbreak of measles, resulting in more than 3000 cases and passionate discussions about vaccines. It served as a painful reminder how important herd-immunity is to the public health. With the first measles appearances in Israel, we founded Mehusgan - an NGO working to raise vaccination rates and improve herd-immunity.

**Methods:** Mehusgan offers 15000 private kindergartens in Israel to join our project for free. By joining, kindergartens require that the children attending them be up to date on their vaccines. Our volunteers check vaccination records, pointing out gaps between them and the vaccination program. Our doctors are available for direct, personal conversations with any vaccine-hesitant parents.

**Results:** Mehusgan has 600 volunteers, including 150 doctors, serving 1000 kindergartens with approximately 40,000 children. 40 communities joined our project as well. Our doctors have spoken with nearly 500 vaccine-hesitant parents, with a 90% success rate - convincing them to fully vaccinate their children.

**Conclusion:** Mehusgan's kindergartens are a revolution in community standards for social immunity and public health advocacy.

## The Clinical Trial Approval by the Ethics Committee is Enough to Guarantee Early Access to Care?

Giulia Vittoria Faitelli<sup>1,2</sup>, Andrealuna Ucciero<sup>1,2</sup>,

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The Ethics Committee (EC) has the role to evaluate and monitor clinical trial protocols, in accordance with current legislation and Good Clinical Practice.

In our context, the pharmacist of the EC Scientific Secretariat (ECSS) set up a database that contains information on 683 approved protocols (2018-2020), highlighting that less than 50% of patients were enrolled and final reports were available just for 68 trials; no scientific papers were received. This analysis shows that a significant number of trials probably do not even start, suggesting that early access to care is not always guaranteed for patients, even if clinical trials had been approved by the EC. A lack of information due to non-transmission does not allow the ECSS to fulfill its monitoring commitment and makes no contribution to clinical research. Therefore, to improve data collection, a proactive approach should be implemented to support the investigator's team, in order to add value to clinical research. The pharmacist of ECSS could play a central role to evaluate if the lack of information is due to a failure in reporting or to investigate the reasons why the trial didn't take place, in an effort to guarantee patient's early access to care.



## Attitudes of College Students in Kosovo about Physician-Assisted Suicide: The Influence of Personality Traits, Self-Esteem, Depression and Suicidality

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**Objectives:** In Kosovo physician-assisted suicide topic is quite in-existent (legally or public debate). The purpose of this research is to get an understanding of college students views and to examine possible links with personality traits, self-esteem, depression and suicidality.

**Methods:** The study was a cross-sectional correlational study. Participants were 94 college students; aged 16 to 26 years old (M=18.44; SD=1.45). The measures used included the Opinions About Physician-Assisted Suicide (PAS), Rosenberg Self-Esteem Scale, Patient Health Questionnaire (PHQ) and The Big Five self-assessment 10 items version.

**Results:** The results indicate that the majority of students sampled not favored physicians assisted suicide, whereas (M=1.75, SD=.937) in an opinion scale with Likert-like response options from 0-4 (strongly disagree to strongly agree). Correlational analyses indicated significant positive correlations between positive opinion about PAS and having a family member with a serious illness ( $r=.217$ ,  $p.03$ ) and suicidal ideation ( $r=.231$ ,  $p.02$ ). There are no significant correlations between positive opinion about PAS with religiosity, having a family member with a serious illness in past, personality traits, self-esteem and depression.

**Conclusions:** Despite the student's negative opinions for PAS there is time and space to open debate among professionals in Kosovo. Personal actual experience with illness and suicidality seems to accept PAS more than other variables studied here.

## Designing A Successful "Medicine and the Holocaust" Course for Medical and Graduate Students Utilizing Significant Learning

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Successful efforts to teach medical students about the Holocaust have been made in recent years; however, calls in the literature for physicians to universally study the Shoah have been scattered, and few medical schools have instituted Holocaust studies as a portion of the formal curriculum.

Since 2010, the authors have taught a "Medicine and the Holocaust" course to final year medical students at two different institutions in the US. This course was designed following L. Dee Fink's Taxonomy of Significant Learning (2003), utilizing multi-modal forms of learning, reflection, and service. In 2016, an all-online graduate course was also introduced utilizing this model.

This paper reports the methods and results from these two courses and suggests designing "Medicine and the Holocaust" courses that are evidence-based, asynchronous, reflective, interactive, and longitudinal. Our experience demonstrates that tremendous financial resources and historical expertise are not barriers in establishing a successful Holocaust course in medical or graduate schools.

Finally, we share five "Lessons Learned" from our teaching experience for medical practice that can be perpetually learned from the Shoah including: (1) commitment to a personalistic anthropology; (2) conscience protection for physicians; (3) rejection of scientism; (4) avoidance of depersonalization; and (5) re-commitment to patient-centered medicine.

## Ethics, Patents and CRISPR? An Examination of Patents as a Novel Form of Technology Governance

Oliver Feeney

University College Cork & NUI Galway, Ireland

Compared to previous techniques of genetic interventions, CRISPR-Cas9, has been steadily moving the possibilities of making effective and realistic genetic changes to emerging realities. To underlie the revolutionary advances in technical capacities, only six years passed between Charpentier and Doudna's seminal 2012 paper highlighting CRISPR, and its possibilities, and the first confirmed cases of humans were born with their heritable genetic constitution gene-edited using CRISPR-Cas9. While governments, international bodies and other relevant stakeholders, try to ensure that the legislative, regulatory and effective ethical, legal and societal frameworks catch up to the technical possibilities, the concern is that the eventual outcome will be either an ineffective mix of partial regulation or an equally ineffective overreaction in terms of widespread prohibition and blunt overregulation. Alongside the technical progress, innovation has also been taking place in terms of ethical guidance from the field of patenting. Sherkow has noted the rise of so-called 'ethical licensing' where institutions, researchers and companies have used their patent control over CRISPR techniques (especially in the case of fundamental patents), to create a form of private governance over uses of gene-editing through ethical constraints built into their licensing agreements. Recently, Parthasarathy has begun an examination of the patent system as an alternative to future regulation of gene-editing technologies. In this presentation, I will evaluate the emerging prospect of patents as a form of ethical governance of CRISPR-Cas9 and will conclude that, so far, this avenue seems to raise as many issues as it seeks to resolve.

## Bioethics and the Future Generation

Ana Claudia Ferraz<sup>1,2</sup>

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In the current time men are worried about a healthy life, in order to avoid suffering, aiming a better quality of life and longevity and, for some people, the immortality. The medical-scientific advances and the dissemination of techniques of assisted human reproduction, which allowed the manipulation of human life in the laboratory, in previously unimaginable proportions, bring to light the need to discuss limits to the use of new technologies applied to medicine. This is because genetic manipulation, in particular, can alter characteristics that are specific to the human species, taking into risk the dignity of the human being, which is the basic principle of democratic States and international norms and treaties. Hence the need to recognize the human being as a total species, regardless of the space and time in which it lives, and the protection of future generations is necessary. The dignity of the human being must be protected not only in the present time but must be guaranteed to every human being born or unborn, that is, the present and future generations. It occurs that the current legal categories do not lend themselves to adequately protect future generations, as a way of guaranteeing their own existence. For this reason, this research is justified in order to demonstrate the need for bioethics to turn to the protection of future generations, as well as the legal system to reformulate classical concepts of private law, to ensure that protection, among them the concept of person/subject of law. Thus, the main objective of this paper is to propose the extension of the legal category "subject of rights" to include future generations and provide them with proper legal protection. To achieve this objective, the deductive methodology is used, fundamentally through the theoretical research line, through the collection of data obtained with bibliographic consultation to the sources pertinent to the theme. Finally, is intended to alert the need for recognition of future generations as a subject of intergenerational rights and, as such, able of legal protection in the present, as well as legal duties of the present generations to the future generations, grounded on the principles of responsibility and precaution.

## The Communication of Death and the Care Challenges

Marileise Roberta Antoneli Fonseca, Flávio César de Sá,  
Lúcia Figueiredo Mourão  
*State University of Campinas, Brazil*

This qualitative study aimed to understand the communication experience of physicians in the processes of death and palliative care in a quaternary hospital, in Brazil. This study, based on phenomenology, enrolled eighteen resident physicians from April 2019 to August 2019, that were required to respond a questionnaire in individual interviews. The questionnaire encompassed five questions as follows: 1) "Would you like to share your professional experience with patients who are not curable?" 2) "Did the undergraduate prepare you to face this situation?" 3) "How do you promote palliative care in your specialty?" 4) "Has your professional experience provided support for your conduct towards end-of-life care?" 5) "Did the patients you attend have their care needs met?" Four categories that make up the experience were highlighted: in-communication in the face of therapeutic obstinacy; the seriously ill patient, his family, and the healthcare team: whose life is it anyway? Therapeutic relationship and educational relationship in care; and the possible ways of humanization of care. The study demonstrated the importance of practical activities in learning in palliative care, the appreciation of multidisciplinary work, the suffering in decision-making of end-of-life patients and the distancing in dialogue and care practices offered to these patients.

## To What Extent Does the EU-General Data Protection Regulation Also Deal with Ethical Aspects in the Handling of Personal Data?

Gerhard Fortwengel  
*University of Applied Sciences and Arts Hannover, Germany*

Data protection within the European Union and, in certain cases, outside this territory, has taken on a different dimension through the EU General Data Protection Regulation, which does not apply exclusively to the field of health research. As a general regulation, however, it also concerns the collection and processing of data from clinical research and, depending on the design, epidemiological studies. Clinical trials are rightly subject to strict ethical standards, which, however, have not been legally binding in the vast majority of cases to date. In addition, the use of more modern and efficient technologies and tools has facilitated the extraction of data from existing data collections and the aggregation and processing of these data, which increases the risk of improper handling of personal data. Legally binding claims to ethical values in connection with the handling of personal data are a means of ensuring an appropriate balance between the technical possibilities and the ethical and moral standards of each individual. The lecture will discuss to what extent, in what areas and in what form the General Data Protection Regulation of the EU deals with ethical aspects in the handling of data from clinical research.

## Against Pandemic: Institutional Responses between Freedom and Authoritative Instances, Ethical and Legal Analysis of the Italian Pandemic Plan 2021-2023

Lorena Forni  
*University of Milano, Italy*

In this oral presentation, after a general description of the Plan, the bioethical criteria that are the basis of the current document will be critically discussed. Attention will also be paid to the issue of allocative justice and the proposed meaning and role attributed to the fundamental right to health will be considered. The problems that emerge from the redefinition of the right to health in the document will be highlighted, to critically discuss whether we are moving towards a new ethical-legal scenario, in which the liberal system is set aside, to favor new authoritative instances.

## Voluntary Sterilization as a New Formula of Contraception of the 21st Century? The Admissibility of a Voluntary Deprivation of Procreation Ability, Comparative Law

Dorota Frankowska  
*University of Warsaw, Poland*

While some are doing their best to have children, others prefer to gain certainty that their intimate life will not lead them to become parents. That's the paradox of the 21st century: people have fewer common values; they prioritize different goals. Voluntary sterilization provides us a perfect depiction of such a situation.

The sterilization does not raise controversies when it is held in a treatment target. The doubts may occur when the purpose is no more medical, but ... practical. Whereas the United Kingdom's law allows Madlener operation as a form of contraception, in Poland such surgery is eligible for grievous bodily injury in the light of the art. 156 of the penal code.

Does the informed consent of a patient legitimize a voluntary sterilization? Some find it legally irrelevant due to its incompatibility with the principles of social coexistence. Would that not mean that Polish criminal law tends to be 'moralistic'? The aim of this presentation is to consider the admissibility of voluntary sterilization in Poland and abroad, taking into account both the voices of the doctrine and the rulings of the Constitution Tribunal, according to which a right to parenthood also has its negative aspect.

## The Physiotherapist Perspective Before Ethical and Bioethical Problems Experienced in His Performance in the Family Health Support Centers (FHSC)

Daniela Ferraz Frauches Carvalho  
FIOCRUZ, Brazil

The physiotherapy began to integrate Family Health Strategy (FHS) in 2008 through the creation of Family Health Support Centers (FHSC), and so inserted into the Brazilian model of Primary Health Care (PHC) and its own work process. With this insertion came challenges to a profession that was throughout its history linked to rehabilitation processes in secondary and tertiary care. Given this reality, it becomes of fundamental importance to describe and critically reflect on the ethical and bioethical problems in the performance of the physiotherapist in the FHSC team. For this, a questionnaire with closed and open questions was applied to the physiotherapists working at the FHSC in the city of Rio de Janeiro, and the content analysis was performed according to the proposal by Bardin. Questionnaires were delivered to two Planning Areas (APs) in the city of Rio de Janeiro. After the questionnaires were delivered, eight were returned and answered. It can be seen from this that the problems related to the physiotherapist performance in FHSC are mostly related to aspects of the relationship between FHSC and FHS teams and within FHSC teams, thus showing the need for a consolidation of the role of FHSC and its attributions in articulation with the FHS. It was also identified the present difficulty of the physiotherapist in relation to concepts of ethics and bioethics, due to the insufficient approach of the theme in its formation.

## Historical Approach to Children during the First 1000 Days of Life and Its Implications on Contemporary Bioethical Debate

Branka Gabric  
Alphonsian Academy, Italy

UNICEF has recently launched the campaign First 1000 days of life pointing out the importance of this period for the future child development. Since then, the notion of the first 1000 days of life has entered the public discourse and medical conferences. And when we look back on history it is easy to notice that human being during his first 1000 days of life was perceived and treated in different ways and with different respect during epochs. Reflecting on the ancient Greek and Roman, medieval, and modern western societies differences can be seen between historical societies/periods as well as within the same societies. On the one hand, there is disrespect toward the little ones while on the other hand there is respect and even the magnificent adoration of them. Our study focuses on the analysis of these different historical attitudes that are still present and it gives a hermeneutical key for their better understanding. The first 1000 days are anthropologically the most questionable period of human life but on the other hand, they are some of the most important for our future biological and mental development, as argues UNICEF, and as such are worthy of being rethought.

## Hans Asperger's Ward for Therapeutic Pedagogy at the Viennese University's Children's Clinic: The importance of Including Pre- and Post-war Years in Holocaust Education

Ina Friedmann  
Institut für Zeitgeschichte/University of Innsbruck, Austria

Recent research has focused renowned Viennese pediatrician Hans Asperger's (1906–1980) career during National Socialism; an equally significant aspect had meanwhile remained in the background: theoretical continuity to before 1938 and after 1945. Asperger became head of his ward in 1935, beginning to develop his scientific ideas during Austrofascism, when biologicistic concepts within social and health sciences were not only popular in Nazi-Germany, but also on the rise in Austria. Being in line with certain NS-dogmas concerning the 'value' of minors, Asperger could keep his post after the 'Anschluss' in 1938 and continue his work without conceptual changes. Never having joined the NSDAP allowed Asperger to continue his career after the liberation 1945.

While a person-centered approach constitutes the setting, most emphasis should be put on the patients subjected to this system of evaluation and categorization. A critical view on their records reveals the authoritarian judgement about minors seen as 'difficult', 'neglect' or 'troublesome'. These views could lead to placement with foster parents, in educational facilities – and during National Socialism at Spiegelgrund, Vienna's child-'euthanasia' facility. Spiegelgrund was closed after liberation – but the view on minors like the ones who were interned there between 1938 and 1945 persisted for decades.

## The Apprenticeship Model for Formation and Education of Healthcare Ethicists

Colleen Gallagher  
The University of Texas, USA

The practice of healthcare ethics involves familiarity with many disciplines. such as biological science, philosophy, faith traditions, and jurisprudence to name a few. Technical expertise in the subject matter alone is insufficient to assist in resolving dilemmas, as one must also be adept at forging relationships through skills such as active listening, effective communication, empathic engagement and rhetoric. Clinical Fellowships are becoming a more common and expected step toward professional practice, particularly in the academic setting. The Apprenticeship Model, whereby the trainee is provided "bedside" teaching and experience under the supervision of an ethicist, provides the necessary instruction for integrated training and practical wisdom in the professional formation. of the future healthcare ethicist. Similar to the tradition of Flexner and Olser, this approach integrates the necessary knowledge and skills and fosters adherence to professional norms. Apprenticeship learning can also afford the trainee an opportunity for professional identity formation through acquisition of values and commitments modeled by others and nurtured through self-reflection and growth. To be successful, the mentor(s) must create a space for the Fellow to discern a vocation and calling in the field. The Fellow must have a safe space to explore personal and professional experiences and changing attitudes. Our experience will be discussed.

## The Holocaust, Human Dignity, and Health Care: Reflecting on the Past to Protect the Future

Stacy Gallin<sup>1,2</sup>

<sup>1</sup>Maimonides Institute for Medicine Ethics and the Holocaust, USA

<sup>2</sup>Misericordia University, USA

The Holocaust reveals an extraordinarily low point in human history in its denial of dignity to human beings and its singular use of medically sanctioned genocide. Science and medicine were used as justification for the labeling, persecution and mass murder of millions of people grounded in a hierarchical system of classification where people were valued based on their perceived worth to society. The moral ethos of the medical profession shifted from caring for the needs of the individual to focusing on the best interests of society, including ridding the public of those deemed 'unfit.'

Are we any better off today? Throughout the world we are fighting battles over access to basic health care, structural and institutional racism, mental health care, unethical medical experimentation, equity of care, medical genetics and end-of-life care. Respect for human dignity is being threatened yet again by the promise of scientific advancement and societal progress. What can we do to ensure that history does not repeat itself? This presentation will explore resources for investigating the ethical implications of the Holocaust for current issues in medicine and human rights endeavors and suggest ways for individuals to actively participate in protecting our future by learning from our past.

## Once Again "Engineering Life": Current Developments, Epistemological Aspects, Ethical Issues

Gösta Gantner

University of Heidelberg, Germany

Recent developments in Synthetic Biology emphasize the intention to »engineering life«. Which concept of »life« underlies these projects? Heuristically, certain reductions are very productive. What effects do such ideas have when they transcend the realm of their own epistemic community? What ethical implications can be observed when a constrained concept of life radiates to other fields, such as law or healthcare? On the one hand, Synthetic Biology contributes to societal, medical or ecological ends. On the other hand, many risks can already be identified with this technology. Such issues have been treated for several years. Nowadays it is necessary to find an interdisciplinary framework that deals with the increasing attempts to »create life«. This framework should not only react retrospectively but also reflect latest trends. It should also involve the public. The »Responsible Research and Innovation« (RRI) approach seems to be appropriate to examine the ethical, legal and social aspects associated with the paradigm of »engineering life«. My presentation outlines the advantages and limitations of RRI as a participatory process to explore benefits and risks of such an emerging technology.

## Challenges in Teaching Learning Process of Newly Implemented Module on Bioethics in Undergraduate Medical Curriculum in India

Barna Ganguly<sup>1,2</sup>, Rui Nunes<sup>3</sup>

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<sup>2</sup>International Institute of Organizational Psychological Medicine (IIOPM), Australia

<sup>3</sup>University of Porto, Portugal

**Background:** National Medical Commission of India introduced Competency Based Curriculum in Medical Education for undergraduate medical students in 2019 with a new module namely Attitude, Ethics and Communication (AETCOM) across the country. There was a consensus for teaching medical ethics in integrated way suggesting dedicated hours in each phase of undergraduate training. AETCOM module was prepared as a guide to acquire necessary competency in attitudinal, ethical and communication domains.

**Objectives:** This study was aimed to identify challenges in teaching and learning process of newly implemented AETCOM module. Methods: It was an observational study with structured questionnaire for students and teachers at various medical schools. Based on the data, in-depth interviews with medical teachers were undertaken.

**Results:** Challenges were perceived by both students and teachers. The students had mixed perception, facing difficulties in passive learning with scarce resource materials. Challenges identified from teachers were lack of knowledge and skills required for teaching Bioethics, logistics in managing large number of students in stipulated time frame, interdisciplinary integration - both horizontal and vertical and assessment program in terms of Miller's Pyramid.

**Conclusion:** There are definite gaps at different levels in implementing the new module of AETCOM which call for revision and correction.

## Palliative Care: Law and Policies in México

Bernardo Garcia Camino, Robert T. Hall

Universidad Autónoma de Querétaro, México

The lack of palliative care in México has been pointed out by different international organizations (Human Rights Watch, The Lancet Commission Report, The Economist). Although the legal framework has been improved dramatically, there are still systemic structural issues about the interpretation of the law that hamper the implementation. An empirical study showed physicians in México do not know what is legal and what is not legal with respect to terminal care treatment and even have clear doubts about what is ethical. Based in this study, we propose the development of policies at the institutional level, which apply the actual legal framework instead of further efforts to modify the law. We are now involved in a research project with the State of Querétaro Secretariat of Health to test a program of implementation through Palliative Care Plans. We believe that education, training and small administrative changes can make palliative care a reality for all Mexican people.



## Autonomy Constraints on the Internet of Health

Maximilian Gartner  
University of Bologna, Italy

Individuals are increasingly interacting with or are affected by algorithmic agents belonging to a class of context-aware services; this pattern does not exempt the domain of health. These automated processes are not ethically neutral, and particularly not autonomy-neutral. This contribution investigates the salience of such processes to individual autonomy.

This presentation identifies three dimensions of individual autonomy that are most salient to understanding constraints imposed by such processes: (1) intrinsic autonomy, (2) informational autonomy and (3) relational autonomy. On the basis of the above, this presentation outlines an abstracted mapping of interaction characteristics between individuals and algorithmic agents in the domain of health, both directly and indirectly. Of particular interest are (a) the medium of interaction, (b) the perceived accuracy, precision and trustworthiness, (c) the assertiveness of information, and (d) general context of use.

Using the findings of these abstractions, this presentation outlines an approach to describe and compare algorithmic agents by their vectors of influence, i.e. by their potential to be enabling or transferring autonomy constraints. This makes visible a subset of questions pertaining to the ethical impact of such agents.

## Does Privacy Matter if you are Dead? A Healthcare Perspective

Aiste Gerybaite<sup>1,2,3</sup>  
<sup>1</sup>University of Turin, Italy  
<sup>2</sup>University of Bologna, Italy  
<sup>3</sup>University of Luxembourg, Luxembourg

The article suggests that in the era of Big Data, data collection is so widespread that individuals cannot assess each data processing to determine whether it includes sensitive personal data or not. Thus, particular ethical and legal issues arise in digital healthcare. Firstly, within the EU, the GDPR, is individual-centric, and as a general rule, any processing of data concerning health is prohibited. Secondly, the paradox between the GDPR principle of data minimization and Big Data may lead to issues for computer scientists providing healthcare solutions. Lastly, as noted by Van der Sloot et al, legal systems are based primarily on the rights and obligations, and Big Data challenges this since the data processing is often transnational and ensuring legally binding obligations is difficult. This may not be the best starting point when thinking about Big Data solutions in healthcare as Big Data does not always include sensitive personal data nor is necessarily individual-centric. Thus, the researcher considers whether the GDPR, whilst protecting fundamental human rights to privacy, may lead to the risk of stifling of technological research and innovation within healthcare and how this in turn may affect the right to health.

## Patients' Rights: Limits to Justiciability and the Need for Capacity Building

Rita Gião Hanek  
University of Lisbon, Portugal

This paper analyses whether and how patients' rights are being enforced in Portugal. Based on the review of case law, as well as annual reports, decisions and recommendations by the Health Regulatory Authority, the Inspectorate General of Health Activities and the Commission for Access to Administrative Documents, the paper identifies the main shortcomings and trends.

The results show that most cases on patients' rights that reach courts are cases on the right to information, namely on the issue of consent. In filing and processing complaints, healthcare providers, patients, lawyers and judges often miss the distinction between the consumer protection patients' rights approach, and that based on norms of international human rights and bioethics. This is in detriment of justiciability and adequate enforcement of patients' rights. More importantly, the paper argues that failure to frame these cases as human rights violations removes the pressure off of the authorities and results in missed opportunities to improve the system in place.

On this basis, the study emphasizes the need for States to foster patients' rights through patients'/human rights education and training, as well as involving healthcare providers in development of codes and guidelines in order to mainstream patients' rights throughout the health-care system.

## New Technologies in Human Gene Editing: A Legal Glimpse into an Issue in a Dire Need for Guidelines

Tamar Gidron  
Zefat Academic College, Israel

The buzz around the almost too-good-to-be-true potential of the new technologies in human gene editing, especially those that are literally offering tailor-made babies, has become noisier during the last few decades. Indeed, the Chinese twins that Dr. He introduced to the world in November 2018 are only the tip of the iceberg. It is obvious that these technologies are about to change the face of future societies. Yet the swift proliferation of these technologies only just echo the silence of the lawmakers- global and local. This is a typical phenomenon also in other interactions between new technologies and the law, such as privacy issues on the internet and GMO food.

Indeed, some of the more advanced countries that are open to medical innovations have already adopted normative guidelines for human genetic enhancement. Israel, for example, decided on a moratorium that will be lifted in the near future.

This paper aims to highlight some of the many legal issues that beg for a comprehensive solution before the legislator is called to lay down a politically correct, socially sensitive and technologically implementable draft that will – like in the US on the one hand and the UK on the other hand – pave the way to a delicate workable *modus vivendi*.

## "Medicrulturization": A Socio-cultural Utilization of Medical Technologies and Practices

Netta Gilboa-Feldman<sup>1</sup>, Nissim Leon<sup>1</sup>  
Bar-Ilan University, Israel

Our suggested presentation deals with recruitment, construction and utilization of medical technologies and practices, as socio-cultural strategy.

We suggest that proactive processes by which society harnesses medical means in order to enable compliance with socio-cultural values, norms, needs and practices, can be referred to as what we call "Medicrulturization" - A term which offers a socio-cultural perspective on the nature of some of society-culture-medicine's relations.

We will demonstrate this by focusing on the Jewish Ultra-Orthodox religious-traditional community and present some situations in which socio-cultural related intricacies and impediments, such as stigmatization, bio-cultural discrepancies and public embarrassment, are being resolved by utilizing medical solution such as genetic tests, hormonal intervention and PGD. While some 'Medicrulturization' processes may raise bioethical dilemmas, other can provide accessibility to medical services otherwise not exploited.

The concept of "Medicrulturization" is relevant for future research, since socio-culturally driven implementations of medical technologies and practices can be found not only in religious traditional societies, but also in modern ones - Caesarean sections upon maternal request or non-reconstructive aesthetic cosmetic surgeries are just two optional examples. Hence, we suggest that the concept of 'Medicrulturization' carries a potential of providing a useful analytical tool for further examination.

## Mad, Sad or Bad?

Digvijay Goel  
Southland Hospital, New Zealand

**Introduction:** Arbitrarily architected, poorly validated and inadequately researched, borderline personality disorder exists uneasily in the no man's land between the mad and the bad. Many regard this, not unjustifiably, as a non-diagnosis, reflecting social or moral judgement, rather than a naturalistic clinical entity, separated from related disorders by zones of rarity, with little by way of systematic research to support its nosological status.

**Objectives:** While a wide range of psychosocial/pharmacological interventions have been tried, no credible therapeutic strategy has emerged. Its relationship with bipolar disorder remains enigmatic. The symposium will address the rhetorical question posed by BJPsych some years ago: can personality disorder be treated?

**Methods:** It is proposed to brainstorm through this melee of conflicted evidence/opinions and attempt a semblance of consensus.

**Results:** At the conceptual level, there is disagreement with the categorical approach adopted by both the DSM- 5 and ICD-10 in defining the diagnostic criteria for different types of personality disorders, with little predictive value and even lesser therapeutic utility. The situation is compounded by the high prevalence of co-morbidity, including substance misuse, from time to time in the same patient. The role of psychopharmacological interventions, though used more often than not, remains controversial.

**Conclusions:** The proposed ICD-11 model appears more pragmatic and nearer real-life practice. However, several critical issues remain unresolved, none more important than the negative emotions these patients evoke amongst mental health professionals and emergency services who have to deal with their suicidal/para-suicidal behaviour. Appropriately designed studies are needed to generate doable options.

## Inside the Violence: Nature and Incidence of Family Homicides in Central Italy from 2000 To 2021

Gabriele Giuga, Gian Luca Marella, Giorgia Piizzi,  
Alessandro Mauro Tavone, Maria Chiara Clericò, Petroni Giulia,  
Saverio Potenza  
University of Rome "Tor Vergata", Italy

**Introduction:** Family murder represents a significant percentage of voluntary homicides (49.5% in Italy according to Eures). The aim of the current study is to assess the features of this phenomenon in the last 22 years in Central Italy.

**Sample:** The study includes the analysis of 40 family murders' dossiers from the archive of our institute of legal medicine in the period between 2000 and 2021. For each case, 13 features of victim and/or perpetrator were extracted for descriptive statistical analysis.

**Conclusive Discussion:** The perpetrator is usually a man (mean age 37) who kills at home by stabbing multiple times with a kitchen knife his partner, for passionate motives.

The victim is more often a woman, with multiple incised wounds mainly located in the chest.

Parricide represents the second most common occurrence. In the past women were more involved both as victim and as perpetrator in this kind of crime.

The present study instead shows a clear prevalence of N = 33 male authors against N = 8 female authors. Modest social background with a low schooling is predominant. However, previous criminal records and psychiatric pathologies were infrequent.

## WhatsApp Application as an Informal Telemedicine Platform

Yonatan Goffer  
Schneider Children's Medical Center of Israel, Israel

**Introduction:** The WhatsApp application is a popular application. Data on its use by patients to consult physicians is scarce.

The aim of this study was to assess the extent of this App as a medical consultation platform, possible risks and benefits and ethical dilemmas it brings.

**Methods:** A prospective cross-sectional study was conducted in 2019. Data were obtained through questionnaires filled by pediatricians. The frequency of WhatsApp consultations, clinical features and recommendations given, were compared between different pediatrician populations.

**Results:** 304 pediatricians filled questionnaires; 129 pediatric residents and 175 specialists. 302 (99.3%) give WhatsApp consultations on regular basis. The majority (65%) reported 1-5 consultations/week. Over 9 consultations/week were more common among specialists compared to residents (24% vs 5.4%, p0.001). Clinical cases were the most common consultation (77%), mainly, rash (37%), fever (21.5%) and trauma (12%). Media was attached in 72% of clinical cases. There were no differences between physicians according to workplace. No disclaimer, on the risks associated with the informal consultation, was added in 33% of cases.

**Discussion:** WhatsApp medical consultation is common, especially among specialists. Attached media is a major advantage. Ethical and legal aspects are not fully considered. Guidelines are further needed.



## Nothing About Me Without Me! Ethical Aspects of Using Big Data to Improve IVF Provision

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Big Data can revolutionize the medical field, in particular in fertility treatments. Much has been written about reducing the time from diagnosis through to follow up as well as reducing medical error. Faith has been placed in Big Data as a tool to significantly improve health care services for patients, ultimately to save lives, and in the case of fertility treatments to help make lives. In this article, we focus on the influence of Big Data in the field of fertility treatments. This field is at the intersection of the mental, physical, and emotional well-being of patients as well as the fiscal well-being of the health system and/or the patients themselves, depending on which parties pay for the services. Patients struggling with infertility rely on numerous medical professionals to achieve their goal of parenthood. For this reason, Big Data has the significant potential to aid couples and individuals struggling with infertility. This paper considers the ethical and social considerations of IVF provisioning in Israel and how the use of Big Data can help improve the success rates of "take-home babies" while protecting the health of the mother and the financial solvency of the national healthcare system.

## Rethinking Informed Consent? The Metaphysical and Ethical Implications of the Placebo Effect for Clinical Approaches to Depression

Jonah Goldman

Yale University, USA

A growing body of evidence suggests that placebo drugs are far safer than antidepressants and similarly effective for treating depression. However, replacing antidepressants with deceptive placebo treatments has not been seriously considered in the bioethics literature, since deceiving patients is antithetical to patient autonomy and its concretization in the process of informed consent. Yet findings on the placebo effect undercut commonsense distinctions between medications, provider-patient communications, and the environment of treatment as a whole, in turn raising deep challenges for standards of truth-telling and explicit consent upon which common bioethical arguments against deceptive placebos stand. I draw out these metaphysical implications of the placebo effect and explore the ethical motivations for shifting clinical approaches to depression away from antidepressants and toward deceptive placebo treatments. While practical impediments to implementation ultimately render such a treatment paradigm ethically nonviable, the challenges I raise nevertheless demand attention in future bioethical and policy work if patients with depression are to be treated both ethically and efficaciously.

## Management: Does the Consumer Perspective Matter?

Agata Golawska Moody

Southland Hospital, New Zealand

Borderline personality disorder has been researched for a nearly four decades. However, the amount of research focused on a patient's perspective is limited. The overall management of a condition is poor and often leads to unintended harm. In the light of the relational character of the illness, better understanding of a patient's perspective can lead to more effective clinical interventions.

Diagnostic manuals focus mainly on observable characteristics of a condition. This observer centered understanding of an illness shifts attention away from the core issues experienced by sufferers such as struggling with life, feelings of inadequacy, not belonging and wishing not to be alive. Sufferers have to cope not only with severity of an illness and self-destructive drives but also with a burden of a diagnostic label and the stigma attached to it.

On the other hand, the stigma associated with a diagnosis, the responsibility for risk and treatment outcomes, leads clinicians to distancing themselves from patients and this in turn amplifies feelings of rejection and symptoms severity.

An increased sense of connectedness rather than objective symptom reduction should be prioritized in treatment. This can be achieved by continuously attending to unhelpful dynamic between a sufferer and a clinician.

## Impacts of COVID-19 on EU Free Movement Law

Iris Goldner Lang

University of Zagreb, Croatia

COVID-19 has demonstrated the fragility of EU free movement rules when faced with an unknown virus of such magnitude and strength that it threatens our lives, health systems, economies and society. The aim of this presentation is to show the dynamics between the threat of COVID-19 and the rules imposed as a response to the pandemic, which have impacted the functioning of the EU internal market and the Schengen area. The presentation will concentrate on the application of precautionary principle and public health restrictions, caused by COVID-19, to free movement of persons in the EU. The analysis will lead to three conclusions. First, it will be shown that the decisions to apply free movement restrictions and the logic followed in the EU COVID-19-related documents can be viewed as a triumph of precautionary principle. Second, it will be argued that the implementation of precautionary principle has a transformative effect on the application of the principle of proportionality in EU law. Finally, it will be shown that COVID-19 has emphasized and increased the difference between the conditions for the applicability of public health restrictions, when compared to restrictions based on public policy and public security grounds.

### **Assessment of Psychiatric Disorders in Actions Against Social Security INSS in Federal Court of São José Dos Campos, São Paulo**

Marcia Goncalves<sup>1</sup>, Fernando Camara<sup>2</sup>

<sup>1</sup>UNITAU, Brazil

<sup>2</sup>Instituto Stokastos, Brazil

The present study evaluated psychiatric disorders among patients who claimed for social security insurance in São Jose dos Campos – SP (Brazil), for the period of one year, in order to investigate the most common pathologies among those. A well-dened sociological prole was recognized on this study, suggesting that affective disorders in adult men with poor psychosocial links are frequent cause of occupational and social disability.

### **Art and Human Rights**

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The wonderful capacity of the human being, to create knowledge, moves in several areas. Some of them validated by the scientific method, easily linked to sciences such as physics, chemistry, astronomy, mathematics and even disciplines such as anthropology, archeology and psychology. In addition to these alternatives, verifiable and validated by institutions such as the State and the school, there are and have earned their place those that are developed through *Ars Tekne*, better known as arts. Thus, we have as references, the visual arts, where the creator committed to his historical moment, seeks to register some of the deepest inequalities of his time, through his plastic work.

It will be important to take a tour of the works, their creators and the geographical moments and coordinates where creation sees the light, as well as the importance of its teaching for new generations to generate spaces and people with respect, rather than tolerance.

All this, based on the Universal Declaration of Human Rights from 1948: Article 27 - part 1. Everyone has the right to participate freely in the cultural life of the community, enjoy the arts and participate in scientific progress. and in the benefits that result.

### **The Holocaust, Lessons for Medicine: A Way to Teach Professional Values**

Esteban González-López, Rosa Rios-Cortés

Universidad Autónoma de Madrid, Spain

During Nazism, some doctors and nurses were the executors of the State Racial policy and participated in the forced sterilization and extermination of people with mental or physical disabilities. They also conducted medical experiments in concentration and extermination camps.

The behavior of those doctors allows us to reflect on several aspects of Bioethics in the present day Medicine such as the care for people regardless of race, social or medical condition, the influence of economical and political issues and research limitations.

Since 2012 we have been teaching the course *The Holocaust, lessons for Medicine*, <https://afly.co> in the Universidad Autónoma de Madrid, Spain, after a call from our university to create elective subjects concerning Human Rights. The objectives of the course are to compare the characteristics of current professionalism with actions carried out by doctors and nurses during the National Socialist period and to develop respectful attitudes towards gender, cultural and health.

Every year we conduct a survey on the students' opinions on some bioethical issues before and after the courses. The results show how our subject can be a contributor to developing some professional values such as the need to establish research limitations and the knowledge of the strength of a doctor's power within a relationship with the patient. We have also visited with our students as a pedagogical tool some Holocaust and Medicine related-sites in Poland and Germany.

### **The Regulation of Direct-to-Consumer Genetic Testing and Its Legal and Ethical Implications in South Africa**

Amy Gooden

University of KwaZulu-Natal, South Africa

Recent advances in science have enabled genetic testing to be conducted inexpensively, expeditiously, and directly by consumers, therefore allowing individuals access to their genetic information without the intervention of a healthcare provider or health insurance company. This technology can assist individuals to better manage their wellbeing and conserve much needed healthcare funds. Yet, direct-to-consumer genetic testing is not free from controversy primarily due to potential human rights infringements and a lack of regulation.

This presentation explores whether direct-to-consumer genetic testing should be legally regulated in LMICs like South Africa. I approach this issue from a human rights perspective, with particular reference to the rights to privacy, autonomy, and dignity. I suggest how these technologies should be regulated in LMICs so as to maximize their benefits whilst simultaneously avoiding the risks.

It is necessary to examine the legal and ethical implications of direct-to-consumer genetic testing and establish sound policies in South Africa and globally. My presentation focuses on the need for legalization and regulation of direct-to-consumer genetic testing in the African context. On a practical level, I propose that model regulations should be developed that can easily be adopted by LMICs.

## The Ethico-Legal Challenges of Stem Cell Technology in Malaysia

Nishakanthi Gopalan  
*University of Malaya, Malaysia*

As one of the emerging technologies, stem cell (SC) continues to make headlines not only for its therapeutic potential but also for its ethico-legal concerns. The stem cell technology was introduced to Malaysia no more than 20 years now. For SC research, they were mainly preclinical studies, and a few were clinical trials, which were reviewed by the National Stem Cell Research and Ethics Subcommittee (NSCERT) (2006). Without a law or policy, research was guided by the Guideline for Stem Cell Research and Therapy (2009). While SC researchers and practitioners in the public sector would in general adhere to the SC Guideline, the bench to bedside practices among the private healthcare providers lack oversight. This, in particular, has a significant implication on the SC therapeutic treatment among the locals as well as tourists through medical tourism industry. The Guidelines for Stem Cell Research and Clinical Translation by the International Society of Stem Cell Research (ISSCR) is a new SC guideline that take into considerations Malaysia's unique cultural and religious context. However, without a law or policy to provide stature, the guideline may not be effective in providing sound oversight. This argues for Malaysia and other low middle income countries to regulate SC-based technologies, either by formulating a SC law or embedding provisions in assisted reproductive technology (ART), biomedical or bioethics law. This would give authority and jurisdiction that the SC guideline needs.

## The Ethics of Online Peer Support Groups for Mental Health

Jordan Gorenberg  
*University of Oxford, UK*

There is a growing body of literature on the ethics of social media, artificial intelligence, and professionally provided online support groups for various types of mental illness. With increasing technological advances, compounded by the COVID-19 pandemic, the therapeutic landscape of mental health care is changing as remote therapy and support are considered viable options for people unable to access in-person care. Online peer support groups are a popular alternative or complement to more formal treatments due to their low cost and accessibility. However, little is understood about the ethics of online peer support groups. Drawing on fieldwork from the social media platform Reddit, I outline the benefits and challenges of online peer support groups for mental health. In this presentation, I argue that while online peer support groups offer opportunities to share experiences and information, connect with others, and become educated, they risk bullying, crisis management, misinformation, and exposure to harmful content for users. Because online peer support groups are not professionally moderated, the unique challenge to such groups is the role of the moderator as a non-professional in gatekeeping the community. Such ethical issues need to be carefully considered by moderators, current and prospective users, and mental health practitioners.

## Organ Donation between Family Members-Ethical and Moral Dilemmas

Oded Gorni  
*Sheba Medical Center, Israel*

55% of kidney transplants from a live donor in Israel derive from a family member to another. Organ donation between family members seems to raise less ethical and moral dilemmas as opposed to altruistic donations between foreigners. Therefore, the Israeli Organ Transplantation Law (2008) has established facilitating mechanism regarding donations within the family.

But is the different reference justified?

In my presentation I will show data from the accumulated experience in the field of kidney transplants at Sheba Medical Center in Israel, through which I would like to examine whether the data supports or weakens the assumption that a donation within the family is an expression of solidarity, is self-evident and has no ulterior motives.

What can we learn from the difference percentage of male and female donors? Can we ignore economic motives when it comes to blood relationship? And in general, is it possible to talk about free will and consent when it comes to organ donations in the family?

In light of all these, I will try to suggest new standards to examine full lucid comprehension and free will when it comes to organ donation in the family and recommend criteria for approving or disapproving donation between relatives.

## Islamic Jurisprudence and Processes of Solving Bioethical Dilemmas

Ewa Górka  
*Jagiellonian University, Poland*

In Islam, bioethical dilemmas are discussed primarily within the framework of Islamic jurisprudence. On a practical level, questions about the permissibility and ethical evaluation of medical interventions are directed to Islamic jurists and their councils. They respond by issuing a legal opinion (fatwa), which in most cases is non-binding. As many of the bioethical problems are related to the modern development of sciences, much of the legal deliberations are based on interpretative efforts. Lack of supreme authority, diverse views and conditions of scholars, adherence to the teachings of various schools of law, and other factors cause pluralism of opinions of Islamic scholars. In effect, research on Islamic bioethics is focused more on chosen juristic positions concerning bioethical problems, rather than theoretical aspects of legal reasoning over them. This presentation aims at systematizing knowledge about how Islamic jurisprudence is practiced in reference to bioethical cases. It shows the process of legal reasoning in bioethical cases and identifies characteristics of its outcomes, such as diversity of opinions and arguments, individualization, variability, and responsiveness of fatwas. Such systematization allows further reflection on the condition of contemporary Islamic bioethics.

## Human Dignity for the Elderly: A Paradox

Debora Gozzo

Universidade São Judas Tadeu, Brazil

"Human dignity" is a vague concept by all means. This vagueness inevitably contains a wide range of ideas about the magnitude of the term. For sure, however, it can be understood as the respect that one has to show for others. Otherness plays a big role in this context. In today's society, the end of life is being ever more postponed due to the advances of medicine and biotechnology, and new ways of gaining immortality are being searched - while at the same time old people are being more and more neglected. This is a great paradox of our times. In developing countries, they often do not have the access to proper health care. If they have such means, it is, however, very common that their voice might not be heard for they are old. Living wills might not be taken into account and relatives might decide differently or even contrarily to the original will, making it such unfeasible to know what was really wanted by the person concerned for the time before the end of his or her life. It is already time for the world to pay attention to elderly people and to revisit the concept of human dignity for the elderly.

## Ethical Problems of Preimplantation Genetic Diagnosis

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Today there is a sufficient arsenal of molecular genetic methods for the effective prevention of genetic diseases. However, a number of issues need to be addressed so that these opportunities are used effectively and socially acceptable in Russia. These issues relate to legislation, public awareness regarding the prevention of genetic diseases and ethics. It is also important to consider the whole range of factors that affect risk assessment in a situation of moral choice. For example, studies in Russia show that an embryo without mutations and an embryo with heterozygous carriage are considered to have equal chances of transfer in the IVF cycle. However, one sick child in the family is considered as the reason for the preference of the embryo without a mutation. Approximately the same logic determines the ethical choice in the situation of a curable monogenic disease. The ethical situation of correlation assessment: 1) criteria for medical indications for termination of pregnancy, 2) criteria for the selection of embryos during preimplantation genetic diagnosis, and 3) requirements for gamete donors in assisted reproductive technology programs is even more complicated and require well-defined decisions. The research was supported by the Russian Science Foundation, project No.19-18-00422.

## Immolation Predictors: Results of the STIGBATE Study in France

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Burn patients are often stigmatized in our society. Few studies are devoted to the analysis of the circumstances of occurrence of the burn, including suicide attempts. In France, since 2015, there has been a self-immolation every two weeks in front of an administration: public square, parking lot for business, courtyard of school, tax centre.

The aim of this presentation is to present some of the results of the prospective study carried out in France on the social impact of burns in visible areas: the STIGBATE study.

In patients with severe burns after voluntary self-immolation, we find personality specifications and a recurring environmental contexts: Personality very involved in his work, great sense of duty; Very strong confidence in its system (administration, company); Significant workload: investment commensurate with demand, exceeding capacity, dehumanization; "Authorities" alert: no response provided; Betrayed trust: Impasse; Protest against injustice: militant action: immolation.

Burn is a social and societal disease. Occupational medicine must be able to recognize warning signs of discomfort at work which, for some patients, can allow prevention of self-immolation.

## The Construction of Medicolegal Alienation in Physicians Practicing in Liminal Informal Clinics Servicing Undocumented Migrant Patients

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**Background:** Globally, undocumented migrants have relied on informal clinics for their healthcare services. Empirical explorations of physicians' moral, ethical, and legal consciousness surrounding practising within this context remain lacking. The present study sought to contribute to this gap.

**Method:** Constructivist grounded theory was applied to qualitative interviews with 16 physicians working in informal clinics in Sweden.

**Results:** Findings synthesized physicians' experiences into three categories: Ambiguity in navigating illegality, due to awareness of vulnerabilities surrounding patient-safety and own involvement, whilst simultaneously feeling enriched through interactions in the clinic; Being exposed to patients' accounts of structural violence and social injustice; Experiencing isolation in practice, when discovering professional limitations and feeling severed from the conventional medical institution.

**Conclusion:** A novel dimension of legal consciousness theory, coined as medicolegal alienation, was identified and introduced. When functioning as arbiters of patients' rights within the conventional medical institution, questions surrounding undocumented migrants' deservedness force physicians into a position of moral, ethical, and professional dissonance. Struggling to dictate their own practice, they are propelled out into informal clinics, in search for congruence. Through this process, physicians become alienated from both their profession and from legality.



## The First Nation-wide Study on Facing and Solving Ethical Dilemmas among Healthcare Professionals (HCPs) in Slovenia

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**Objective:** To study the main types of ethical dilemmas among HCPs and how do they solve them.

**Methods:** We conducted a cross-sectional, survey-based study among HCPs in 14 Slovenian hospitals. Data collection took place between April 2015 and April 2016.

**Results:** The final sample size was  $n = 485$  (385 or 79.4% females), response rates for HCPs working in secondary and tertiary level institutions were 45% and 51%, respectively. Three hundred and forty (70.4%) (very) frequently encountered ethical dilemmas, i.e., waiting times for diagnostics or therapeutic treatment, suboptimal working conditions due to poor interpersonal relations on the ward, preserving patient's dignity and relations between HCPs and patients. Physicians and nurses working in secondary level institutions, compared to their colleagues working in tertiary level institutions, more frequently encountered ethical dilemmas with respect to preserving patient's dignity, patient's information protection, relations between HCPs and patients. In terms of solutions, physicians, nurses and other HCP most commonly discuss ethical dilemmas with co-workers (colleagues), with the head of department or physicians convene a medical council meeting.

**Conclusions:** Waiting periods for diagnostics and treatment and suboptimal working conditions are among the most important ethical issues by HCPs in Slovenian hospitals.

## Changing our Moral Dispositions: An Assault on Identity?

Jennifer Guiho  
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Debates on the ethics of human enhancement are often centered on concerns of fairness. Critics assert that by improving 'positional goods' (e.g. height), enhancements place non-users at a disadvantage. There is, however, one subset of human enhancement that does not warrant these same concerns: moral bio-enhancement. These enhancements are characterized by the biomedical manipulation of human motivation to generate conduct that is deemed moral or virtuous. They have the potential to benefit non-users by making individuals less impulsive, less aggressive and more cooperative. Due to their inability to effectively appeal to concerns of fairness, proponents of the anti-enhancement position have focused on concerns of identity in their moral evaluations, positing that possible benefits of the enhancement would be outweighed by the loss of personal identity that would ensue. In this paper, I respond to these critics by focusing on the compatibility of autonomy and enhancement. I argue that the voluntary use of moral bio-enhancement is consistent with a 'higher-order moral trait' or 'second-order desire' to improve one's moral dispositions, eliminating so-called threats to identity. Further, I argue that arguments in favor of the coercive use of moral bio-enhancement cannot overcome identity concerns, limiting the ethical use of moral bio-enhancement to instances of consent.

## Mental Health Literacy and the Stigma of Mental Illness in European High School Students

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The paper highlights the differences in mental health literacy of high school students from 4 European countries. The data was collected through a questionnaire on mental health and mental illness stigma administered within the project "Memory Against Inhumanity" co-funded by the European Union.

**Methodology:** The sample was composed of 512 students from high schools in Italy, Greece, Romania and Slovenia. The school program included a historical section on the stigmatization strategies used by totalitarian regimes in Europe to justify crimes against mentally ill and disabled people. It also included training on the concepts of mental health and mental illness, and the administration of a questionnaire that investigated their knowledge about aetiology, onset and prevention of mental disorders.

**Results:** We will be presenting how the different variables investigated (e.g. country, demographic characteristics and access to school psychological services) influenced the answers to the questionnaire. The data was analyzed through a logit model.

**Conclusion:** These elements can guide targeted interventions in the school environment, aimed at reducing stigma, promoting access to services and encouraging the support of others towards those in need of mental help.

## Necessity of Identifying and Respecting Patients' Values: Ethical Issues

Thibaud Haaser, Sylvie Marty  
Université de Bordeaux, France

Person-centered cares have become the leading paradigm in Medicine. The attention health professionals must pay to patients' values is even more promoted and concrete processes as shared decision-making are daily examples underlining the need for physicians to adapt cares to patient's singularity. The legitimacy of the person-centered approach is based on the need to preserve patients from authoritarian medical decisions. A constant attention to patients' values is also a way to enhance patients' adhesion to therapeutic proposals.

But the currently promoted attention to patients' values raises practical questions: what do we concretely mean when we are talking about values in this context? The term "value" refers to an idea of moral references or ethical action guides. Probably, "respecting values" is another word to point out the imperative to respect patients' autonomy and dignity. But in concrete situations of illness, during which massive affects occur, should not values be understood as representations, expectations or desires? Those are cultural and psychological elements that can be discussed and even criticized in case of misinterpretations. Looking for values to identify and to respect is an unexpected task for health professionals and current medical education does not propose any support for such a delicate exercise.

## Whose Microbiome is it Anyway: The Ethics of Microbiome Ownership in Relation to Indigenous Peoples

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The human microbiome – the co-evolved collection of microscopic organisms living in and on the human body – is profoundly tied to human health and is itself influenced by human cultural and lifestyle factors. Several studies have now highlighted unique qualities, such as increased diversity or unusual species, in the microbiomes of Indigenous peoples worldwide. Hence, the microbiomes of Indigenous peoples may be of particular interest to researchers seeking to understand the roles of cultural practices, ancestry, and industrialization in microbiome-linked diseases. Adequately addressing questions of ownership, group and individual interests in the microbiome, and benefit-sharing from such research will be essential to ethically advance this field. However, ethical discussions of the microbiome to date have largely been conducted from an industrialized Western perspective. As Indigenous peoples are increasingly included in microbiome research, it is imperative that these discussions consider Indigenous contexts and perspectives. Here, we draw together existing scholarship on microbiome ownership and patenting, human identity and the ‘superorganism’ concept, and Indigenous views of nature, in order to illustrate the cultural specificity of microbiome ownership norms and consider how Indigenous perspectives might be translated into appropriate systems to recognize Indigenous peoples’ interests in the microbiome.

## Teaching Ethics to Undergraduate Students

Eryn Hassemer

Milwaukee School of Engineering, USA

Most individuals learn ethics at home, at school, in religious settings or in other social settings. Sometimes ethical norms are so ubiquitous that one might be tempted to regard them as commonsense. Therefore, it is important to instill a set of moral principles in our undergraduate students. At the Milwaukee School of Engineering (MSOE), BioMolecular Engineering (BioE) students analyze a real-life example of an ethical situation that they have encountered at school, at work or their personal life that have tested their ethical behavior. Students recognize their problem and classify it, identify the potential issues in their situation and make a prediction as to which actions will have the least chance of bringing harm to others. Then the possible and probable course of action is analyzed along with evaluating the potential consequences of each course of action. After a thorough examination, the students decide on the best course of action. This assignment allows students to examine the Golden Rule of Ethics which is the principle of treating others as you would want to be treated.

## Telemedicine in Indonesia

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**Objective:** Knowing whether the application of telemedicine has been supported by written policy documents on ethics and law and trying to collect data about goodness and unwanted things in the field of ethics and law in the application of telemedicine in Indonesia.

Telemedicine using medical information and technology is currently developing in Indonesia

There has been a decision by the Ministry of Health about this and also there have been documents issued by Indonesian medical Association and several written Appeals from several specialist association organizations in Indonesia.

In this paper, we will discuss whether legal and ethical documents have been able to anticipate ethical and legal issues in the application of telemedicine.

The ethical review covers: 1. patient and physician relationship; 2. Patient privacy; 3. caution application of new theories; 4. financing.

## How Healers Became Killers: Teaching Medical Ethics through the Holocaust

Patricia Heberer-Rice

United States Holocaust Memorial Museum, USA

The Holocaust—and Nazi Germany’s use and abuse of medicine—can teach important lessons regarding today’s bioethical dilemmas. The Nazi “euthanasia” program, their unethical medical experimentation on human subjects, and their medical perpetrators like Josef Mengele fascinate medical students; and can be used to teach traditional history lessons about the Holocaust as well as underpin today’s quite sophisticated bioethics debates. More and more medical faculties in the United States and abroad are attempting to integrate Holocaust history within the scope of medical ethics training. But medical school curricula are dense; and the ongoing emphasis on scientific and technical training leaves little time for studies in the history of medicine or in the humanities.

Teaching the Holocaust at medical faculties is an important mission, in that it expands the students’ historical knowledge as well as their ethical awareness, thus aiding them in becoming better medical professionals and citizens. But how does one go about it? This paper proposes the unique challenges of teaching about physician and medical establishment roles in the Nazi era and applying lessons of the Holocaust to contemporary ethical issues in medicine.



## Can Compulsory Hospitalization of Schizophrenics Be Justified? Schizophrenics' Autonomy and Paternalistic Policy

Min Heo  
Seoul National University, South Korea

In 2016, South Korea abolished compulsory hospitalization of psychiatric patients, especially schizophrenics. This abolition was affected by a movement for their human right, which invoked their autonomy as an important reason against compulsory hospitalization.

In this paper, I will analyze the movement's argument in the light of two concepts - autonomy and paternalism. Defining paternalistic policy for an autonomous agent as a policy which is aimed for increasing her interests but against her legitimate judgement, then we can analyze justice of compulsory hospitalization in three aspects: interests, legitimacy of judgement, and autonomy. Firstly, compulsory treatment is good for schizophrenics in terms of critical interests, and harm caused by limiting their liberty, which is only experimental interests, can be overwhelmed by aforementioned good. Secondly, refusal of hospitalization cannot be regarded as legitimate judgement because it is dubious whether schizophrenics' judgement is structurally coherent and substantially proper. Finally, it seems doubtful whether schizophrenics are fully autonomous agents, if we understand autonomy as claim and think its prerequisite is recognizing others as autonomous agents. Thus, compulsory hospitalization is not paternalistic and can be justified for schizophrenics' interests and impoverished autonomy.

## Sustainability in Healthcare: Choosing Wisely Norway as a National Voice Against Medical Overuse

Stefan Hjørleifsson<sup>1,2</sup>  
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Waste and harm from medical overuse are a fundamental problem to healthcare systems. Costs keep increasing, and high-tech innovations often provide marginal benefits while also increasing availability-driven demand and promoting an individual and collective experience of endless threats to health that may in itself be unhealthy – and ultimately unsustainable. Choosing Wisely is an international initiative to address medical overuse (overdiagnosis and overtreatment) led by healthcare professionals. In Norway, nine healthcare professions have joined their forces in the Choosing Wisely initiative. A national campaign with the topic “more is not always better” is currently being conducted to inform the public about overdiagnosis and overtreatment.

The 1987 report Our Common Future that introduced the concept of sustainability into international policy debates was the work of the United Nations Brundtland commission led by Gro Harlem Brundtland, medical doctor and former Norwegian Prime Minister, who was later to become secretary general of the World Health Organization. For these historic reasons, Norwegians may be especially primed to address issues of sustainability in healthcare. In this presentation Hjørleifsson, who chairs Choosing Wisely Norway, will reflect on the prospects of redesigning healthcare so as to avoid harm through medical overuse.

## Empathy, Normativity and the Holocaust

Aric Hluch  
The Ohio State University, USA

Empathy is frequently championed by philosophers, physicians, and historians when describing the atrocities committed during the Holocaust. The term itself has become a major buzzword in popular media. Many have postulated that advocating for more empathic responses to various ethical dilemmas would improve the human condition. The problem with empathy is the lack of sound judgment and reasoning that may accompany it. Normative statements cannot be gleaned from empathy alone; reason and objectivity must inform ethical decision-making in a pluralistic society. If empathy led to the formulation of normative judgments, then the field of ethics would be superfluous. Without a circumspect approach to ethical dilemmas, social problems, and the Holocaust, empathy fails. Psychologists and philosophers tend to presuppose that normativity follows from empathy, but the events during the Holocaust, current trends in philanthropy, developments in modern medicine, and human behavior in general prove that simulating the emotions of another person is not necessarily adequate for truly ethical decision-making. Without discussing the limits of empathy, bioethics and Holocaust studies will not fully benefit from suggestions to imagine how other people may feel when they are involved in ethical dilemmas.

## Secondary Use of Health Data for Precision Medicine

Chih-hsing Ho  
Academia Sinica, Taiwan

Many biomedical projects have been relying on large consortia of repositories, such as networks of biobanks, to increase the overall size of bio-samples and data for statistical significance. Nevertheless, the increasing need for transmission and linkage of health data for secondary usage has also brought new challenges in translational research. The current models and privacy frameworks for the secondary use of health data focus predominately on techniques and rules of anonymization and de-identification. These data-centric perspectives fail to adequately address issues such as data control, access and sharing, all of which are imperative to data subjects in terms of deciding how they would like their health information to be used for future research. This talk will investigate these challenges, especially with regards to the secondary use of health data in precision medicine. It aims at proposing a transparent and community-based data sharing model to improve the pitfalls of data-centric models for the secondary use of health data in translational research.

### 30 Years on from the Establishment of the Human fertilization and Embryology Authority (IVF regulator) in the United Kingdom: Is it Now Time for a Broader, Bolder Regulator to Address Issues of Genetics, Commercial Genomics and Big Data?

Gemma Hobcraft  
London & Doughty Street Chambers, UK

This oral presentation will examine the appropriate form of regulation for 21st Century Bioethics. Is it time to stop regulating in silos given emerging and cross-border issues in genomics (commercial or otherwise), genome editing and big data?

2020 marks the 30th anniversary of the establishment of the Human Fertilization and Embryology Authority – that trailblazed in relation to regulation of assisted reproduction in the United Kingdom. Thirty years on this regulator is not empowered to regulate issues that have emerged since its inception, relating to, for example, direct-to-consumer genetic testing (which can have a direct and significant impact on gamete donors and donor conceived individuals). Is it time for a broader, bolder regulator to address the bio law, bioethics and genetic challenges of the 21st Century?

### On the Importance of Acting Solidaristic to Improve Knowledge of Medications Used During Pregnancy

Marieke Hollestelle, Rieke Van Der Graaf, Miriam Sturkenboom, Johannes Van Delden  
Medical Humanities, University Medical Center Utrecht, The Netherlands

**Introduction:** There is still a lack of knowledge concerning medications used during pregnancy. It has been argued that solidarity is of key importance in changing the status quo for medical domains where a poor evidence base exists regarding treatments. This paper explores whether and how enactment of solidarity can be stimulated to improve knowledge of medications used during pregnancy.

**Method:** We apply the concept of solidarity formulated by Prainsack and Buyx to the situation of pregnant people.

**Outcome:** In the case of pregnant people, there is currently an ethical imperative to be solidaristic. Although solidarity cannot be imposed, we propose that actions of solidarity can be stimulated by perceiving solidarity as empowerment, meaning that relevant stakeholders explain what certain groups can do to improve their own situation by acting solidaristic. For the context of pregnant people, empowerment means 1) to create awareness about their status quo, 2) to explain how scientific research can help close the knowledge gap, and 3) to explain how pregnant people themselves can contribute.

**Conclusions:** Acting solidaristic can help to improve knowledge of medications used during pregnancy. By understanding solidarity as empowerment enactment of solidarity can be stimulated among pregnant people and other relevant stakeholders.

### Global Psychiatric Access: The Problem and Possible Solutions

Richard Holbert, Uma Suryadevara, Joseph Thornton  
University of Florida, USA

Access to psychiatric care is a problem globally. Only 1% of the global health force work in mental health while 45% of the world's population live in a country with less than one psychiatrist per 100,000 people. With the increasing disease burden, promotion, prevention and treatment programs are inadequate and those present are hampered by cost, inefficiencies, and limited resources. We will define the problem with global statistics and also focus on the burden caused by lack of access. Possible solutions for the global psychiatric access problem are numerous and we will discuss the ethical dilemma surrounding the driving forces behind these solutions. Integrating mental health into primary care has been one solution studied. Other possible answers include decreasing cost, increasing efficiencies, educating the mental health work force, enhancing the number of psychiatrists and other mental health care workers, population and community-level platforms, open access clinics, among others. We will review the literature on solutions for providing psychiatric care for all of those in need focusing on the integration of mental health into medical and non-medical systems.

### Female Genital Mutilation Prevention Orders: Is the Law Fit for Purpose

Joseph Home<sup>1</sup>, Andrew Rowland<sup>1</sup>, Felicity Gerry<sup>2</sup>, Charlotte Proudman<sup>3</sup>  
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<sup>3</sup>University of Cambridge, UK

**Introduction:** Performing Female Genital Mutilation (FGM) is prohibited within the United Kingdom by the FGM Act 2003. Within the Act, there is a legal instrument available to protect victims and those at future risk of FGM: an FGM Protection Order (FGMPO).

**Aim:** This paper aims to evaluate the implementation, effectiveness and impact of FGMPOs.

**Methods:** A 'Freedom of Information Request' was sent to the Ministry of Justice, requesting data on the number of FGMPOs applied for and granted (October 2015 - June 2019). This data was compared to the number of known cases of FGM recorded by the Health and Social Care Information Centre and NHS Digital.

**Results:** Preliminary results show a large disconnect between the number of FGMPOs applications and known recorded cases of FGM. In the quarter April - June 2019, there were 35 FGMPO applications made. This is a stark contrast to the NHS Digital figure of 995 newly recorded FGM cases in the same period.

**Discussion:** The introduction of FGMPOs requires full evaluation as there is insufficient scientific evidence to show that FGMPOs are currently effective in protecting women and girls from FGM. Barriers to the implementation of FGMPOs are discussed, in addition to possible solutions.

### **Applying Narrative Authority to Build Healthcare Practices to Effectively Recognize and Serve Muslim Patients, particularly women, in a Predominantly Non-Muslim Community**

Fahmida Hossain  
Duquesne University, USA

The norms and practices prevalent in Islam, as they apply to healthcare, are little explored in non-Islamic communities. Western care providers, in this time of modern technology and medicine, often unknowingly make Muslim patients feel uncomfortable, unseen, unheard, and self-conscious or angry. This means for many, the traditions and mores of Muslims are unknown or misunderstood, especially concerning women. Having an understanding of these practices will help non-Muslim care provider to respond to Muslim patients in a culturally sensitive ways. The paper, relying on Muslim women as a focal point, suggests that Western practitioners must come to recognize a Muslim woman as a person in need of care; a person—not a religious or culture abstract—with a story that includes specific beliefs, practices, and worldview. I suggest a powerful way to understand and serve this population is by knowing their stories and coming to see the "other-as-self." As both an approach and working tool I present the concept of Narrative Authority as a guide for health care providers to ensure that the viewpoints, expectations, perspectives, and religious and cultural norms of diverse patients are recognized, understood, respected, and incorporated into the best practices.

### **The Cultivation of Ethical Awareness and Competence for Ethical Decision-Making for Clinical Nurses in China**

Min Huang, Jia Chen  
Central South University, China

With the "healthy China" strategy and the concept of holistic nursing care put forward, good ethical basis and ethical decision-making ability become an important prerequisite for clinical nurses to implement humanistic nursing, and it plays an important role in enhancing nurses' moral sense, building a respectful, consultative and equal nurse-patient relationship and helping patients rebuild their social functions. However, there is a lack of systematic and continuous re-education and training on ethical knowledge for clinical nurses, and there is no training on nurses' clinical ethical awareness and ethical decision-making ability. Therefore, this paper proposes a combination of hospital training and independent practice to train clinical nurses' ethical skill, which include systematic ethics lectures, simulation training, case analysis and other ways to enhance the clinical nurses' ethical awareness and ethical ability. Meanwhile, the clinical nurse should further enhance the learning effect through independent reading, case report and patient experience feedback. Furthermore, more attention should be paid to nursing ethics in hospital publicity, and nurses' ethical practice should be included in the service quality and performance evaluation system, to promote the ethical awareness and ethical decision-making ability of clinical nurses.

### **Finding Value, and Values, in the Tangible: Nishida Kitaro's Pure Experience Theory**

David Howell  
Milwaukee School of Engineering, USA

A central concept in inclusive pedagogical practice is empathy: the instructor strives to understand and empathize with students. People need to be accepted and recognized for their special and unique spirits. To best understand "other", one must first be able to see beyond themselves, a task that is difficult in cultures that propagate narcissistic prerogatives. Nishida Kitaro, the founding father of the Kyoto School of philosophy, advocated for "pure experience," a Buddhist metaphysics that enables the individual to move beyond his/her subjectivity through conduct that bridges the gap between self and other. In doing so, a recipe for empathy is created. By looking at education through the metaphysical perspective of Nishida Kitaro — a philosopher who emphasizes action and experience—one can focus on engendering a value driven process in which the one can lose "ego" through experience. This philosophical approach contrasts with 21st century cultural norms, where media (for example) enables cognitive and physical distance between the self and his/her community.

### **Social Media and the Impacts on Medical Behavior and Patient Doctor Relationship in Taiwan: From the View of the Medical Doctors**

Jack Tien-Yu Huang<sup>1,2</sup>  
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<sup>2</sup>Far Eastern Memorial Hospital, Taiwan

Social media had become important parts of life. While lots of medical information is shown on the social media, with no reviewing system about the contents, many people are affected deeply, no matter right or wrong, about their medical seeking behavior and the interaction with doctors. Many doctors' daily practice is modified, too. Therefore, we survey the medical information on the Facebook, Twitter, Instagram, YouTube and Internet news in Taiwan. We chose three most popular articles about medical information according to the click through rate (CTR) and gave them to different ages of doctors with different specialists and different working places (medical center, local hospital or clinic). We had depth interview with them and analyze the transcript. The education in Taiwan about media literacy is lacking for general population. Also, the medical education about digital professionalism is scarce. All the interviewees admitted that they changed their medical practice even if they knew it was wrong. Over-treatment or under-treatment were quite common. The root cause analysis showed that the peer effect, afraid of medical dispute and the legal issue, and lacking medical knowledge other than their specialists are the reasons. The impact of social media affected the medical practice in doctors, medical seeking behavior in general population, patient doctor interaction and the process of share decision making. Proper education and possible regulation are important in Taiwan.

## Psychiatric Clinic as a Setting for Clinical Ethics Consultations

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A psychiatrist is faced with ethical questions daily. We present two cases involving patients suffering from severe mental illness in which there were ethical dilemmas about pregnancy termination.

Case 1: A 36-year-old woman, five weeks pregnant, treated with medication for schizoaffective disorder, living with her mother and sister. Her father had died of Duchenne muscular dystrophy and she was a carrier for this disease. She asked the psychiatrist to assist on decision making on whether or not she should terminate her pregnancy.

Case 2: A 27-year-old woman, 22 weeks into her second pregnancy. She was hospitalized for the second time due to a psychotic episode. She did not use any psychotropic medication between the two hospitalizations. She did not want to proceed with her pregnancy.

In the first case, medical facts were in favor of proceeding with the pregnancy, but it was terminated by patient's request. In the second case, medical facts were in favor of pregnancy termination, but the patient kept the baby.

Having analyzed situations similar to these in psychiatry, it is no longer questionable whether or not psychiatrists have sufficient education in the field of clinical ethics to assist patients with such difficult decisions.

## The Challenge of Open Science to Brain Patents and Intellectual Property Protection

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Patents protect the intellectual property (IP) of innovators for the purpose of establishing unique rights to a novel product and enabling widespread adoption and investments for financial gain. In health care, patents conventionally protect innovations involving methods and devices, but protections of naturally occurring products such as human tissue and brain regions have encroached on this domain over the past few years. In the brain in particular, patents have been granted to protect not only a methodological intervention for a disease, but the behavior-altering condition it causes and the underlying affected regions. Alongside the inherent dubious ethical nature of this practice, our findings from expert interviews to date suggest that the principles and intentions of Open Science today are challenging such protections in terms of benefit to research and clinical care, return of value to investors from the public sector such as government agencies, and even opportunities for training new generations of neuroscience leaders and inventors. We will examine and discuss this unfolding international debate and offer insights into the empirical ethics research and strategies for non-restrictive IP needed to resolve emerging tensions before they forestall progress intended to ameliorate the human condition.

## Towards a Reconstruction of the Concept of Bioethics

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<sup>1</sup>University of Palermo, Italy

<sup>2</sup>University of Valencia, Spain

Drawing up a critical study about the genealogy of the concept of bioethics, the aim of this presentation is to point out the aporias and paradoxes that are hidden in the mainstream bioethical literature. Questioning both the 'responsibility approach' introduced by Potter and developed by Jonas and the 'principlist' turning point, the argumentative path intends to underline that both concepts of bioethics are not able to perform the normative expectations that are been produced around it over the years. In the par's construes of the presentation, we will try to trace a way for a reconstruction of the concept of bioethics, brings it together again with the philosophy of Fritz Jahr and, especially, with the traditional notion of ethics, understood as a reflexive science and not as a pragmatic discipline.

## Ethical Management of Incidental Findings in Emergency Care: A Critical Interpretive Literature Review

Renata Iskander, Carolyn Ells

McGill University, Canada

Incidental findings (IFs) are findings discovered in the course of care that are unrelated to the primary purpose for which a test was ordered. Some IFs have implications for patient autonomy and welfare. IFs are common in emergency department (ED) settings, with approximately 34% to 45% of visits leading to such findings. We conducted a critical interpretive literature review to explore current practices regarding identification, disclosure, and management of IFs in EDs, and to identify ethical challenges that require research focus and policy reform. A critical interpretive literature review was conducted to identify relevant literature to guide ethical management of IFs in ED settings and preliminary results include 79 articles. Most literature presented the frequency of IFs in these settings but did not report on patient disclosure rates or follow-up rates. Empirical studies included in the review do not address ethical principles or patient preferences on disclosure. The literature reveals numerous suggestions to manage IFs in EDs, including implementation of automatic feedback or alert mechanisms, clarification of responsibilities within treating teams, and improvements to patient documentation. Final interpreted results will be presented and discussed, with attention to ethical implications and challenges.



## The Legal Validity of Informed Consent to the Use of Neuroscientific Mind Reading

Timo Istance  
University of Antwerp, Belgium

It is expected that in the near future it will become possible to use neurotechnologies to read a person's mental state. Informed consent, as a key requirement in the context of healthcare interventions, will be required when neurotechnologies would be used to read a patient's mental states as a part of that person's medical treatment. In the literature, ethical issues have been highlighted that would arise with regard to providing informed consent to mind reading. These ethical problems are diverse and may vary depending on the purpose (e.g., psychiatric purpose; the assessment of capacity), the specific technique used (e.g., fMRI-scans; deep brain stimulation), and the context in which it is used (e.g., clinical context; forensic context). In this presentation, I will discuss several ethical challenges for informed consent to mind reading in a clinical context. Subsequently, I will examine how these challenges may impact upon the legal validity of the consent provided. Finally, I will provide some recommendations on how these challenges may be usefully addressed to guarantee valid consent.

## Making Sense of Public Interest in Healthcare and Health-related Research: An Ethico-Legal Analysis

Zahra Jaffer  
University of Edinburgh, UK

In the UK, 'public interest' provides a lawful basis for processing health data. It is being relied upon to justify certain actions under the law, but we do not have a robust understanding of the concept and its workings. The problem we face is: how do we move forward in those instances when we do not have a robust and defensible conceptualization of public interest and of how to assess public interest claims? In order to address this problem, my research provides an ethico-legal framework for assessing public interest claims in both the healthcare and health-related research contexts. An ethico-legal framework will be helpful for clarifying the concept and providing it with ethical legitimacy, and for enabling assessments on public interest claims to be made with ethical robustness. As such, ethics is pivotal to both the procedural and substantive aspects of public interest. Therefore, where and how ethics should be incorporated into the ethico-legal framework is a crucial question. I will present an outline of this ethico-legal framework, which will serve as a useful decision-making tool in both the healthcare and health-related research contexts, taking account of each.

## Moral Injury in Healthcare: What is it and What Can We Do?

Rebecca Jeyaraj  
King's College London, UK

Avedis Donebadian, father of quality assurance in healthcare, said, "It is the ethical dimensions of individuals that are essential to a [health] system's success".

The practice of medicine is inherently moral. The doctor-patient relationship is grounded in the notion of the doctor as one who will put the needs of their patient first. However, increasing numbers of doctors are leaving the profession. The distress and dissatisfaction that many experiences have long been attributed to "burnout". Recently, the term "moral injury" has been used – not without controversy – to reshape the way we think about clinician distress. Moral injury shifts the locus of control to a wider system which may compel clinicians to act in a way that they feel conflicts with their patients' best interests.

This presentation will highlight the differences between burnout, moral injury and depression among healthcare professionals. It will next discuss the contributing factors to such distress, particularly among junior clinicians who represent the future of the field. Finally, the presentation will explore ways to address the causes of this distress, in order to improve job satisfaction, retention of the workforce and ultimately, quality of care for our patients.

## How to Balance HIV Patients' Privacy and the Public's Health Safety: An Ethical Dilemma about Partner Notification

Wenjing Jiang, Xianhong Li  
Xiangya Nursing School of Central South University, China

By the end of 2018, nearly 1.25 million people were living with HIV(PLWH) in China. A bunch of literature showed that the incidence of unprotected sex was high; the rate of partner notification (PN), and partner HIV testing was low. Ethically, it is indisputable to leave the PN to PLWH to protect personal privacy, because it is the most direct and effective ways to avoid discrimination. However, in reality, PLWH usually hide their HIV status from partners and even practice unprotected sexes, which leads to potential infection.

At present, PN mainly depends on the moral consciousness of PLWH. There are no relevant laws to solve this issue in China. Considering the balance between privacy and public health, we propose several recommendations. First, the PN guideline could be improved by emphasizing the patients' PN obligation initially; however, the health department should notify partners at a specific time. Second, related social support and counselling services should be provided to patients in terms of PN in the healthcare setting. Third, education on non-judgmental attitudes towards multi-sexual orientation should be integrated into the healthcare setting, considering the high, increasing HIV epidemic among homosexual men, and most of them would marry heterosexual women in China. Finally, we must realize that all the rules and procedures carried out should be culturally sensitive and appropriate to fulfil the ultimate goal of protecting human rights.

## Health and New Genome Editing Techniques

Joaquín Jiménez González<sup>1,2</sup>

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Few issues raise more debate than the intervention of the germ line to improve the human species. The new genome editing techniques allow cutting and adding genes for health-related purposes, to design the human genome and, therefore, people. The latest events, which have eluded international consensus, seem to show that this is possible. Given the benefit that the good use of these techniques can have, it seems probable that the human being will use them in his condition to improve his quality of life. The question is to what end we are going to do it. We will define in the exhibition the conditions that must be established for its use, after specifying a state of normality in health and its genetic improvement. We will specify the absolute character that genetic improvement must have at the social level, and other necessary characteristics such as its positive, measurable and desirable effects. We will also establish if equitable access to the test is possible and face its consequences and difficulties, such as the creation of genetic elites, which should never become social elites, and if the human being can cross the border of his condition to reach another dimension to species level.

## Put Your Own Oxygen Mask on First: Nurses as Wounded Healers

Kristen Jones-Bonofiglio

Lakehead University Centre for Health Care Ethics, Canada

The concept of the wounded healer was created by psychologist Carl Jung. Healers may be drawn to their work because of past wounds and/or become wounded in the course of their work. To use the metaphor of a warrior, nurses are often wounded warriors who must navigate the difficult ethical terrain of today's complex practice settings. For the past 40 years, experiences of moral distress have been explored among careers with a close proximity to the suffering of others. Further, related concepts such as compassion fatigue and burnout have been discussed in the context of the need for ongoing self-care and reflection. However, health care providers' own suffering has gone largely unacknowledged. Recent concepts, such as moral injury and nurse-specific trauma, have become hot topics of discussion that attempt to reveal the deep soul wounds that may occur. This new language allows for a more holistic understanding of traumatic experiences and their consequences. Legislation implemented in Ontario, Canada, has now recognized trauma as a legitimate workplace hazard for nurses, in addition to other first responders. New language supported by legislation will allow for better opportunities to build capacity for compassion satisfaction, joy, and thriving in the work of caring.

## Genetic Immunization: Enhancement or Medical Intervention?

Tess Johnson

University of Oxford, UK

The prospect of using genome editing to modify the human germline raises many bioethical issues—among them, whether editing aimed at enhancement may be acceptable. Some medical interventions that contribute to individual or population health are accepted, despite technically constituting enhancement, as opposed to treatments. Such interventions include immunization, which in preventing infection and reducing disease transmission, enhances immune response rather than ameliorating an existing health deficit. Here, I argue that if immunization is rightly accepted as a medical and public health intervention, then genetic immunization—that is, immunity to specific infectious diseases induced via genetic modification of human embryos—should be accepted on the same grounds. My argument first explores the reasons for accepting traditional vaccination interventions. I go on to draw an analogy with genetic immunization, based on shared morally relevant considerations that support vaccination acceptance. Finally, I consider objections to the argument before concluding that whilst genetic immunization may constitute an enhancement, it also constitutes a medical intervention, and should be treated equivalently to traditional vaccination interventions insofar as the two are relevantly analogous.

## Does David Boonin's Desire Argument for the Wrongness of Killing Successfully Rebut Don Marquis' 'Future-like-ours' Argument with Regards to the Presumptive Wrongness of Abortion?

Cameron Joseph

University of Cape Town, South Africa

Following the landmark ruling by the state of Alabama to restrict most cases of abortions in May 2019, the question of the moral permissibility of abortion and the moral status of a foetus has been jolted back into the limelight of public discourse with a polarization not seen since the Roe vs Wade ruling in 1973.

Hence, there is a need to revisit some of the most relevant theories which inform the abortion debate. Don Marquis' Future-Like-Ours (FLO) argument roots itself in the present deprivation of an entity's future of value. David Boonin's argument from desire rests on the capacity of an individual's nuanced desire to continue existing.

Marquis' FLO argument provides an account which elucidates the wrongness of killing and renders most abortions morally impermissible. Boonin's desire account produces similar outcomes in most cases to Marquis' FLO argument. But it fails to do this with regards to the recovering comatose patient who has lost his conscious past. As such, although Boonin provides an account which deals with most uncontroversial scenarios, it ultimately does not provide a successful rebuttal of Don Marquis' FLO argument as it fails to provide answers to the uncontroversial scenario which Marquis' argument does adequately address.



## Short-Term International Humanitarian Missions: Results of a Research Study

Patrick Jung, Victoria Carlson-Oehlers, Bernard Cohen,  
Kathleen Miezio  
*Milwaukee School of Engineering, USA*

Short-term international humanitarian missions (STIHMs) are increasingly the subject of research that indicates academic preparation provides significant benefits to both STIHM participants and the residents of host countries. The authors teach a university course that prepares students for a STIHM in Central America. Students learn about the culture of the region as well as ethics based on the principles of Servant Leadership. The course is optional, and about half the students enroll in this course prior to their first STIHM. Our research involves a ten-year, longitudinal, mixed-method survey administered to students before participating in a STIHM. The control group consists of students not enrolled in the course; the intervention group consists of enrolled students. Results of this research indicate students enrolled in an academic preparatory course exhibit a greater knowledge of the host culture and express greater confidence when participating in their first STIHM. Enrolled students develop a stronger ethical framework than those not enrolled. Students with academic preparation have a greater ability to carry out Articles 12 and 13 of the Universal Declaration on Bioethics and Human Rights, which call for the promotion of cultural diversity and pluralism as well as global solidarity among human beings and international cooperation.

## Attitude and Awareness about Euthanasia among the People of Thrissur, India

Padmakumar K  
*Jubilee Mission Medical College & Research Institute, India*

Euthanasia and Physician assisted suicide have been legalized in few countries with restrictions and also with certain conditions. In India Euthanasia as such is not mentioned in Penal Code as an offence. But active euthanasia whether it is voluntary or otherwise is a crime. A landmark judgment by the Supreme Court in 2018 held that right to die with dignity is a fundamental right and the court recognized passive euthanasia in India and issued guidelines to execute living will along with procedure to be followed for euthanasia.

In this context a study is conducted among the people of Thrisuur to know the awareness and attitude about euthanasia.

**Method:** Data collected using a questionnaire after taking informed consent. Data like Age, gender, Religion, Educational qualification and profession are included in Section A. Section B contained questions related to awareness about rules and regulations related to euthanasia in India. Questions to assess the attitude of a person towards end of life decisions and Euthanasia is included in section C. Results analyzed using descriptive statistics. Association between various demographic variables are also analyzed.

**Results:** Survey completed with 400 samples. Analysis will be completed by 30th November 2021.

## Dignified Healthcare: Human Dignity as Essential Value in Regulation and Provision of Healthcare

Ramunė Kalėdienė, Kristina Astromskė  
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Research shows that the concept of dignity lacks clarity and unified interpretation, therefore identification and implementation of common core values, ensuring human rights and equal respect to each person is of great importance. We need better understanding, how dignity can be maintained while providing healthcare services by identifying factors that may be considered as barriers to dignity.

The presentation aims to clarify the application of dignity as a core value in health care within the human rights framework of the Council of Europe. With the emphasis on the legally binding international human rights documents, we examined the content of the recent relevant case law of the European Court of Human rights. Analysis showed that in the case law, where the element of healthcare provision is discussed, undignified treatment of a person is most often associated with discriminatory practices, inaccessible healthcare services, disrespect for privacy and inhuman treatment or torture. Such practices are highly dependent on systemic factors, therefore we strongly recommend further research into the peculiarities of the concept of dignity in healthcare, for better targeted legislative and administrative measures could be adopted.

## The Proactionary Principle: A New Approach Towards Germline Gene Editing? A South African Perspective

Tamanda Kamwendo  
*University of KwaZulu Natal, South Africa*

While gene editing holds remarkable promises for the healthcare sector by eradicating hereditary disorders and other infectious diseases such as tuberculosis, the precautionary principle, which is a risk management tool, may impede this useful technology. In as much as the precautionary principle increasingly continues to feature in environmental and health legislation internationally, it has received several criticisms – one of which is assuming worst-case scenarios brought about by gene editing, which may in the long run completely halt this technology. While it is easy to sympathize with this sentiment, it would be naive to hope that we could factor out all the risks of gene editing before they even happen. In contrast, by adopting the proactionary approach, policy-makers will assess the risks of gene editing by using only the available scientific data, and not by the popular perception of its uncertainties – thus favoring freedom to innovate and progress in the health sector. Taking into account other ethical considerations, I argue that the proactionary principle could be a game changer in relation to the actual use of gene editing technology – Crispr Cas9 – in promoting the greater right to healthcare in South Africa.

## Food Labelling: Ethical Reflexion for an Accurate and Equitable Information

Gisèle Kanny, Camille Gravelier, Catherine Astier, Sébastien Lefèvre, Martine Batt, Henry Coudane, Laure Jane Danan  
*University of Lorraine, France*

The treatment of food allergy is based on the avoidance of the offending allergen. The modern diet is characterized by increasing consumption of complex foods and globalization. Allergic consumers are dependent on the accessibility, accuracy and quality of information about the foods they buy. The awareness of this public health issue has led regulators to prevent the risk through legislation on the food labeling. A precautionary labeling attracting consumer attention on the risk of accidental presence of allergens in food as "may contain ..." has been developed. This type of labeling enables manufacturers to limit the risk of litigation, but places allergic consumers face a difficult choice and creates insecurity. The anxiety generated by the risk of a possible allergic reaction induces greater effects on social and emotional life than the allergic reactions themselves. The information provided through labeling is not accessible to all, including illiterate and visually impaired. An ethical reflexion for an accurate and equitable information allowing autonomy of allergic consumers is necessary. International harmonization of legislation would protect allergic consumers and support efficient and secure trade in the global food market.

## Switching Responsibility from Doctor to Patient for Informed Consent

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Informed consent is the form each patient receives when diagnostic and therapeutic procedures are provided. This is a process of managing a patient's expectations; it is not just a signature on a document. It must contain information that implies that the patient has reflected on what he expected and consents. Must be free, aware and informed and can be revoked at any time. In case of intervention without consent, the doctor may face claims for damages and, in certain cases, even criminal liability. The rule of necessary consent must be coordinated with the practices and legal, governing the activity of the doctor. Obviously, if the treatment is not carried out correctly, the possibility of claiming damages according to the rules of damage caused by a medical error, including those that impose mandatory attempts at conciliation before resorting to the Judge, is opened. In this hypothesis, it is believed that the lack of or incomplete information creates for the doctor and for the structure responsibility for damages with reference to those typical consequences of the intervention that occur and with respect to which the patient has not been correctly informed. Informed Consent should be Shared Decision-Making process when the doctor can communicate with the patient what is the best and patient have confidence that even sign that document the physician's responsibility cannot be delegated.

## Compassion in Medical Treatment-Jewish Medical Ethics

Yehiel Kaplan  
*University of Haifa, Israel*

Mercy and compassion are important in medical treatment in Judaism. A Jewish doctor who treats patients should fulfill this task mercifully and compassionately.

The act of visiting patients and the act of providing mercy, empathy and emotional support to these patients are fulfillments of one of the most important commandments in Judaism. The Lord guided the Jew to act in a manner that is an "imitation" of his pattern of activity. This is the pattern of mercy, compassion, kindness, friendship and caring. Ancient Jewish sources state that the commandment to act in a kind and merciful manner has no limitation of size and boundary. The Jewish individual should attempt to add more dimensions to the fulfillment of this obligation and expand its scope as much as possible.

This Jewish perspective should guide doctors and institutions that provide medical services in contemporary society. According to this outlook, the main goal of medical treatment should be comprehensive healing. Not only the treatment of the illness itself but also the alleviation of the patient's pain, agony, and emotional suffering.

Compassion, attention to the suffering of patients, a desire to relieve their suffering, the establishment of a warm relationship, of connection, trust, and cooperation, between those who provide medical services and their patients, should be an essential foundation of medical treatment.

## Inconsistency of Maternity Leave Regulation for Ministry of Health's Contractual Doctors and Midwives in Indonesia

Muhammad Rizky Nur Karim  
*University of Melbourne, Australia*

Leave is a right for all workers. Female workers have special rights such as maternity leave. This was recommended in ILO Convention No. 183 of 2000 about Maternity Leave. In Indonesia, maternity leave rights are regulated in Article 82 of Law 13 of 2003 about Manpower, which states that female workers are entitled to maternity leave for 1.5 months before and 1.5 months after giving birth. In its practice, maternity leave rights do not yet apply to the Ministry of Health's contractual doctors and midwives (PTT doctors and midwives). PTT doctors and midwives, or Government Employees with a Work Agreement (PPPK), should also get the same leave rights. As regulated in Government Regulation 49 of 2018 about Management of PPPK, the duration of maternity leave is up to 3 months. However, Article 13 and 14 of Minister of Health Regulation 7 of 2013 about Guidelines for Appointment and Placement of PTT Doctors and Midwives stated that PTT doctors and midwives are only entitled to maternity leave for 40 days. This creates overlapping rules that cause disparities in rights between PTT doctors and midwives with workers in general. Therefore, this paper will further discuss the problems that arise from these rules.

## The Doctor Who Swims Against the Current: The Ethical Approach

Tami Karni

Israeli Medical Association Ethics Bureau, Israel

A common ethical and professional principle in medicine is that a physician should adhere to the prevailing medical view at that time. What happens, however, when a doctor expresses an opinion that bucks conventional wisdom? On one hand, we want to allow physicians the academic freedom to speak their minds, and indeed, some of medicine's greatest developments emerged from physicians who dared to challenge the status quo. On the other hand, it can be ethically problematic and professionally negligent to speak contrary to fundamental medical principles.

The issue of vaccinations is a prime example of this ethical quandary. It is well accepted that vaccinations are effective and save lives, and the "anti-vaxx" movement is not one usually promoted by professional, medically educated individuals. But what if a physician feels a specific vaccine has side effects that cause more harm than good? What if in the future a vaccine is developed, about which an individual physician has doubts regarding its safety or efficacy?

The Israeli Medical Association ethics committee formulated a position paper with ethical guidelines on these issues, balancing the need to be medically responsible with the right of every physician to stand up for what he believes in.

## Study Case: 2019, A Flight Attendant Dies After Being Infected by Measles During a Flight: Who is Responsible? An Ethical, Legal and Medical Discussion

Tamar Katz Peled

Technion - Israel Institute of Technology, Israel

April 2019; WHO, the World Health Organization, reported a worldwide 300% periodic increase in the number of measles cases (112,163); on July Israel counted 4,292 cases; "Epidemic" was repeatedly used in the media.

Infected during an El-Al flight from New York to Tel Aviv, a flight attendant later died. Who is responsible? The infecting host? The flight attendant herself, for lack of proper vaccination? Her employer, El-Al? Israel, for not declaring an epidemic, mandating free vaccination and supplying sufficient doses? The WHO?

The answer lies at the core of ethical, legal, and medical debates pertaining to individual rights, states liability towards their citizens, the status of international health organizations, economic and public interests, conceptualized terms, legal and psychological significance of vaccination, and public influence of the media. Should international treaties mandate related state actions when necessary, such as during a WHO-declared emergency?

These aspects are discussed in this article, which addresses the vaccination issue from a different and novel perspective: the liability over an infected adult as applicable in our globalized world.

Methodologically, the study developed an ethical-legal responsibility model based on professional ethics theory and analyzed accordingly the relevant texts and actions taken.

## Let's Talk About Sex. [Robots]

Llona Kavege

King's College London, UK

Sex robots are the newest innovation in digisexuality, stirring up tremendous controversy since their introduction about three years ago. Proponents of the technology advocate its potential to replace prostitution, provide therapy for individuals with sexual proclivities that can pose significant risk of harm to others, or serve as an educational tool. Contrarily, opponents of sex robots raise concerns about social outcomes, including promoting sexual violence, and compromising human intimacy.

Most of the literature on sex robots comes out of feminist ethics, moral philosophy, journalism, and legal academia, but there is a lack of insight from scholars in philosophy of technology, science, and design.

This paper addresses that gap by promoting the framework of Value Sensitive Design (VSD) in the creation of sex robots, appealing to designers by outlining moral blueprints meant to develop ethical sex robots. The VSD model stands in stark contrast to the design of the currently available models. The mediation perspective of sex robots explored in this paper allows for a methodical and holistic assessment of the benefits and soft impacts of this technology. This will ultimately aid in refining the technology and in preventing social issues like objectification, and sexualization of the image of women and children.

## Decriminalization of Abortion in the UK: A Survey among Doctors

Dermot Kearney

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**Background:** Abortion remains a criminal offence in the UK, subject to the 1861 Offences Against the Person Act. The Abortion Act of 1967 allows abortion under specific conditions. Pressure is mounting for decriminalization to consider abortion a simple healthcare issue, regulated by the profession.

**Aims:** 1. To ascertain the level of understanding among doctors in the UK of the laws regarding abortion and the level of support for its decriminalization.

2. To promote discussion of these issues.

**Methods:** Doctors in a large teaching hospital in the North-East of England were asked if abortion should be decriminalized and why or why not. Each participant was also asked if their response would have been different if asked whether or not abortion should be allowed without restriction up to birth.

**Results:** A large majority supported "decriminalization" of abortion. When reasons for supporting "decriminalization" were examined, however, it was clear that the majority did not understand the law and were simply supporting existing law. Very few supported allowing unrestricted abortion up to birth.

**Conclusions:** Doctors in the UK have a poor understanding of abortion law and what "decriminalization" means. The majority who support "decriminalization" also believe that restrictions to abortion access are necessary.

## Philanthrocapitalism and Global Health Policy in the Context of Bioethics

Ivica Kelam  
University of Osijek, Croatia

Philanthropy is one of the most popular trends among the world wealthiest individuals. Thanks to immense wealth, philanthropic billionaires have unprecedented power in creating education policy, directing the development of global agriculture and dictating trends in global health policy. Large charities replace state institutions as providers of social services. Because of its size, financial power, and political influence, philanthrocapitalists, such as Bill Gates, successfully embody their vision of global problem solving, focusing on the consequences rather than eliminating the causes. This is particularly evident in the example of creating global health policy. In this paper, we will analyze the impact of the Bill and Melinda Gates Foundation on global health policy with special emphasis on the global fight against infectious diseases such as malaria, tuberculosis, and AIDS using Global Fund and Gavi Vaccine Alliance. Furthermore, we will focus on Gates' influence on creating the World Health Organization global healthcare policy, since the Gates Foundation is the largest private donor of the World Health Organization. In this paper, we will investigate the phenomenon of philanthrocapitalism through integrative-bioethical analysis of the activities of Gates Foundation on an example of vaccination policy, and show that, despite their unquestionably noble motives, we must not leave the creation of global health policy in the hands of the individual.

## Medical Futility, Experimental Treatment and Best Interests

Lynn Kennedy  
University of Edinburgh, UK

Medical decisions for incapable persons are made using the "best interests" test. This concept is vague, and when applied to situations where treatment is deemed "futile", further complexity is added. Neither concept has a universal definition which causes confusion but allows for decisions to be patient-centred and applied on a case-by-case basis. "Best interests" decisions were made using the Bolam test. However, the Law Commission and Butler-Sloss P. rejected this test in relation to best interests. Despite this, Bolam has been creeping into decision-making.

How does the law treat futility decisions in relation to experimental treatment? Bolam has also been applied to futility judgments but this medical treatment concerned is conventional treatment. Where experimental treatment is considered, it is treated as distinct from futility. Once a case is labelled, this determines how it will be treated. If a case is labelled medically futile, the law looks to reasons to stop treatment. Once a situation is labelled as pertaining to medical futility, it is difficult for it to be approached by medical professionals, judges and some media outlets in any other way. Experimental treatment is contrary to understanding surrounding medical futility. It conveys thoughts of innovation, progress and alternatives to abandoning hope.

## Corrective Ethics in the Mid-Century Practice of Separating Twins at Birth

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<sup>1</sup>The Chinese University of Hong Kong, Hong Kong  
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Tim Wardle's film 'Three Identical Strangers' brought attention to Peter Neubauer and Viola Bernard's longitudinal 'Twins Separated at Birth Study' orchestrated by The Child Development Center, Louise Wise Services (LWS) and Columbia University in the 1960's. Wardle creates an engrossing cinematic display of the problematic study by featuring separated triplets who recount their story of separation at birth, reacquaintance and subsequent outrage upon learning of their non-consenting participation in Neubauer and Bernard's study. Four other sets of twins involved in the study have expressed similar crises, anger, and resentment towards their unwilling and unknowing involvement. As such, study is to formally researched and investigated Neuabuer's unethical work through interviews with those involved and examination of primary documents so that corrective steps can be identified to make participants whole. This research served to generate a standard process dubbed by the authors as 'Corrective Ethics,' which can be applied to systematically identify wrongs considered acceptable within the context of their day that are now categorized as unethical by modern bioethical norms. Further, by using the framework of the little-known 'Twins Separated at Birth Study' to generate the practice of 'Corrective Ethics,' the bioethics community to can ensure wholistic evaluation of dated or unethical scientific research that continues to cause harm in participants or their families.

## Ethics Education in Psychiatric Residency Training: A Resident's Perspective

Jessica Khan, Joseph Thornton  
University of Florida, USA

Resident physicians, and particularly psychiatry residents, encounter ethical situations in clinical and professional settings almost daily. Navigating these scenarios in a productive way that aligns with the clinician's values and clinical reasoning requires skill and practice that residents should build over time with the guidance of structured education and mentorship. However, there is often little structured ethics education in residency programs and residents frequently face these difficult situations under-prepared and with minimal support. This can ultimately lead to poor patient outcomes and physician burn out. Educating psychiatry residents in ethics is challenging and few studies have been done to elucidate effective methodologies. This presentation will explore a resident's perspective on the importance of ethics training and how to increase interest and participation of residents in ethics discussions. The presenter will review current literature on the value and implementation of ethics curricula in psychiatry residency programs and discuss the essential role residents should have in their ethics education.



## Ethical and Moral Dilemma Facing Oman National Bioethics Committee

Ahmed Khitamy Al-Badawy  
Sultan Qaboos University, Oman

**Introduction:** There are recorded incidents where children as well as adults are subjected to spiritual healing process, that subsequently ended in their death or permanent impairment.

**Objective:** The objective for this presentation is to make the audience familiar with prevalence of magico-spiritual healing in the gulf regions, and the challenges facing the Oman National Bioethics Committee (ONBC) in establishing guidelines to put an end to this unethical malpractice.

**Method:** This papers reviews and analyses journals, publications, various data, statistics and reports with case application on magico-spiritual healing. Therefore, this paper is in part descriptive and in part analytical and comparative, aiming at evaluating the impact of magico-spiritual healing in the gulf region.

**Results:** Wide varieties of magico spiritual remedies are found to exist and are described in detail. These remedies include inserting nails in the stomach of the sick patients who are assumed to be possessed by evil spirits.

**Conclusions:** The ONBC is facing an ethical and moral challenges in drawing demarcation as well as establishing ethical guidelines between faith-healing and the magico-spiritual healing involving physical innervations in expelling the bad spirit in the body.

## AI as a Medical Device: Is it Enough to Ensure Performance Transparency and Accountability?

Anastasiya Kiseleva  
Vrije Universiteit Brussels, Belgium

The presentation will be based on the upcoming article. The 'black-box' nature of AI algorithms creates the challenges of its use in all the areas where the decision-making process shall be transparent and accountable. One of these areas is the healthcare industry. While transparency and accountability are rather unexplored in the healthcare domain, these concepts shall be first explored and differentiated by its types in healthcare generally and in relation to the use of AI. Following that, the presentation will provide a brief analysis of the current EU and US regulations on medical devices and their applicability to AI-based applications. In the end, it will be concluded that the medical devices regulations can be considered as the initial legal framework for the use of AI in healthcare in terms of safety and performance but shall be extended and further developed in terms of performance transparency and accountability. The relevant reasons will be explained.

## Experiencing Moral Distress: Physical Therapy Students in Practice Learning

Roei Klein, Michal Elboim-Gabyzon  
University of Haifa, Israel

The most common definition of moral distress is that of Andrew Jameton, who argued that moral distress occurs "when the nurse makes a moral judgment about a case in which he or she is involved and the institution or co-workers make it difficult or impossible for the nurse to act on that judgment."

Most research on moral distress has been conducted using nurses as subjects; less is known about the moral distress experienced by other healthcare professions, such as physical therapists.

In undergraduate physical therapy studies, we are taught about patient-centered care, codes of ethics, and psychology to better care for our patients. Public healthcare systems usually consider cost and efficacy factors in the course of treatment. One might be forbidden from taking a specific course of action, which could lead to a moral dilemma (if one shares the same beliefs/rationale) or moral distress if one's hand forced. The curriculum should be updated to include classes related to healthcare management and the study of both the ideals and the reality of public healthcare. This would diminish the moral distress caused by the dissonance between the ideals and professionalism being taught and the compromises that are necessary to aid and treat all those who need treatment.

My aim is to cover existing research regarding healthcare students in general and physical therapy students in particular.

## Patient Safety Interventions Perception in Hospital Staff: Considerations Over the Influence of The Healthcare Environment and the Institutional Responsibilities

Francisco Klein, Laura Favaloro, Sebastián De Franchi  
Favaloro University, Argentina

Patient safety interventions lie on the assumption that the health care community are aware of its procedures and ready to act upon them. We conducted a voluntary survey analyzing this hypothesis. Response rate was 22%, obtaining a total of 335 data (29% from nursing staff and 71% from medical house staff). 77% of responders agreed to the fact that the hospital carries out patient safety improvement measures, while 76% granted that error analysis has led to changes in their work protocols. However, this agreement was weaker when asked about how well these changes were followed-up (51% of agreement). The error reporting system is known by 69% of responders, but 59% have not reported any incident during the last year. The attitude was neutral about how well the quality assurance department communicates the corrective measures taken. Difficulties in communication appeared as a concern for the staff as 44% complained about incomplete information during patient transfers and 36% considered that coordination among different units of the hospital as flawed. Overall, patient safety was considered good to excellent by 93.6% of those answering the survey. We speculate over factors affecting medical errors' reporting and personal and institutional responsibilities associated with its improvement.



## Revising the International Code of Medical Ethics (ICoME)

Otmar Kloiber  
World Medical Association, France

In 1949, one year after the adoption of the Declaration of Geneva (DoG)\* as a "modernized Hippocratic Oath" the World Medical Association published the first International Code of Medical Ethics (ICoME)\*\*. With a number of small changes, the Code stood as an enshrinement of professional values for over 70 years. The Code has become the inspiration, if not blueprint for many national Codes, but over the last decades lost recognition. The recent revision of the DoG led to the need to look into the ICoME as well and examine whether the code still reflects common values and translates them into an understandable and livable deontology. With changes in societies relation to patient autonomy, the value of life, digitization and commercialization of medicine, the WMA conclude it was time to review the ICoME and to develop a new text that better reflects the professions values and how they can be maintained. The tensions visible reflect the current discussion about patient's preferences vs. conscience, data mining vs. confidentiality and privacy, as well as professional autonomy vs. commoditization. In a three year process the WMA seek answers to those questions by discussing with experts and public.

## Regulating Artificial/Augmented Intelligence (AI) in Medicine and Health Care

Otmar Kloiber  
World Medical Association, France

In a current wave of enthusiasm AI is being hyped as the panacea for nearly any unsolved medical problem and it is perceived as the replacement of many physician specialties that soon may be superficial. Both it is not. Seeing the tools like machine learning, natural language processing and other IT technologies as tools to augment natural intelligence has a real chance to change the quality and quantity of medical practice and to indeed improve health, healing, support and palliation\*. It will improve medical education and change our work environment considerably. However, this comes with enormous challenges to patient privacy and confidentiality, to demands on data transparency and validity and equity in service availability and access. Recent developments in the field of artificial intelligence rather point to the commercial exploitation and concentration of benefits gained by new technologies than their contribution to the common good. This raises questions of distributive justice, but also on the ownership of inserted data, which is highly bound to individual contributions and work. Turning augmented intelligence into a common benefit, while respecting individual rights and dignity will require new ethical standards based on shared values and norms.

## Medical Errors Reporting Procedures: Knowledge, Perception, Recognition and Practices among Medical Residents and Senior Staff Members

Mira Kochanovsky, Francisco Klein, Laura Favaloro,  
Sebastián De Franchi  
Favaloro University, Argentina

**Introduction:** Medical errors (ME) remain a central element in patient's safety analysis. The frequency of its recognition and report has not been studied thoroughly. It has been reported that the point at the training trajectory might also be a factor associated with ME management. We designed a survey to study the knowledge, perception, recognition and disclosing practices of residents and senior staff from medical specialties and some of the associated variables.

**Material and methods:** The study is a cross-sectional study among medical residents and senior staff at the Favaloro Foundation University Hospital in Buenos Aires, Argentina. Categories into which data about medical errors were arranged included: 1) the reporting procedures knowledge, 2) perceptions, 3) recognition of ME and 4) reporting were collected. Each element among each category was scored on a 5 points Likert scale. Chi-square test and logistic regression were used for the statistical analysis using SPSS. The significance of p was set at 0.05.

**Results:** We will show the current ME reporting knowledge, perceptions, recognition and practice procedures among medical residents and senior staff from medical specialties. Association between variables defined from data obtained from the different survey categories are also analyzed.

## Corporate Sustainability: Making the Planet a Better Place for Our Children

Dorothy Koech, Alfred Bett  
University of Kabianga, Kenya

Over the past two decades there has been great concern on environment due to a myriad of issues, some being over reliance on fossil fuel, rising of global temperatures and fresh water lakes diminishing. There is great concern on what corporate can be able to do about this. Growing awareness of environmental issues has led to increase in corporate responsibility and sustainability. Corporations have a upper hand on most global issues, therefore corporations can either lead in environmental preservation or its detriment. This paper therefore examines corporate sustainability strategies of corporations with an aim of finding best strategies that can contribute to overall healthier environments while simultaneously improving business outcomes. The paper will concern itself with green marketing which is marketing of environmentally friendly products and services. Every purchase has an effect on the environment therefore the paper will also look at green procurement for sustainability. It will also study sustainable product development, the choices one makes in new product development process will impact throughout the life cycle of the product and directly affect the sustainability of the company, the product and the planet.

## We are ALL Immigrants: Bioethical, Medical and Religious Issues

Claudio Kogan  
UTRGV, USA

One of the biggest ethical issues that America faces today is Immigration. Since antiquity, humans' beings have moved from place to place for a better life. Therefore, migration is, first and foremost, a normal human activity. Human beings have always moved from 'one country, locality, and place of residence to settle in another'. People migrate from the homes of their families or guardians into their own homes. People migrate between regions, cities, and towns.

As an immigrant, I will discuss ethical, medical and religious that I personally experienced and I experience today by leaving in Texas at the American- Mexican border. I will share my experiences dealing with the immigration humanitarian crisis, as a physician, as a bioethics, as a religious leader, and as a law enforcement chaplain.

I will touch upon my lessons and challenges as an immigrant, from the last couple of years. I will reflect upon how my "different hats" answer the Humanitarian Crisis that America lives with today. I hope that my lessons will enlighten other countries and parts of the world that face similar situations. I hope that my testimonies will help the audience to understand the complexity of the situation.

I hope that each country in the world should exercise the principle of autonomy and I wish that its citizens should demonstrate solidarity to every human being. By learning from this presentation, the audience will understand and learn the mechanism of bridging the tensions. These discussions will contribute to strength the knowledge of the participants in a time in which immigrants numbers grow throughout around the world.

## Evaluation of Tissue Directive from the Perspective of Assisted Reproduction

Hana Konecna  
University of South Bohemia, Czech Republic

The use of donated tissues and cells is becoming increasingly important in modern medicine. The EU legal framework is set out in the Directive 2004/23/EC (Tissue Directive), adopted in 2004. Its introduction sets out these ethical principles (18), as a matter of principle, tissue and cell application programmes should be founded on the philosophy of voluntary and unpaid donation, anonymity of both donor and recipient, altruism of the donor and solidarity between donor and recipient." The Position Statement of the Council of Europe „Illicit and unethical activities with human tissues and cells", published at the end of 2018, points out that „the processing and distribution of tissues and cells of human origin has progressively become an "industry" in some settings and donated human material treated as a commodity.

The European Commission published at the end of October 2019 the first formal evaluation of the EU tissues and cells legislation. The evaluation document is now open for discussion, the conclusions of which should lead to a possible reformulation of the Tissue Directive.

The specific use of donated cells is in assisted reproduction. In my paper I will focus on the conclusions of the evaluation in the area of assisted reproduction from the perspective of the principle of anonymity and solidarity, I will analyze possible directions of development and their impacts.

## Bioethical Aspects of Neurorehabilitation Clinical Practice (The Opinion of Bulgarian Rehabilitation School)

Ivet Koleva, Borislav Yoshinov  
University of Sofia, Bulgaria

Rehabilitation is a functional therapy, based on a detailed functional assessment. Neurorehabilitation (NR) is an interdiscipline between neurology, neurosurgery, physical and rehabilitation medicine. In clinical NR-practice we apply holistic and patient-centered approach.

NR-algorithm includes evaluation (based on International Classification of Functioning - WHO, 2001) and synergic combination of natural and preformed physical modalities.

Neurorehabilitation is strongly connected to some principles of the Universal Declaration on Bioethics and Human rights (UNESCO, 2005): Human dignity and Human rights; Autonomy and individual responsibility; Informed consent; Equality, justice and equity; Non-discrimination and non-stigmatization; Social responsibility.

Patients in NR-clinical practice have reduced autonomy and disability, requiring assistive technologies, home adaptations, complex pain management. In terminal cases (especially in geriatrics), we have problems with informed consent and right of euthanasia.

Important bioethical aspects are the interactions between the patient and the NR-team; and between different members of the multi-professional multi-disciplinary NR-team.

Authors will present results of anonymous investigation of the opinion of the staff of NR-Departments of Bulgarian hospitals for long-term care and rehabilitation (medical doctors, physiotherapists, nurses). The NR-team consider bioethics as an important link between NR and human values.

## Where to from Here?

Pratap Kovvuri  
Waikato District Health Board, New Zealand

**Introduction:** Borderline personality disorder is a serious and highly prevalent condition. Conceptualizations of this disorder have remained controversial and continually evolving. Although we now have effective treatments for this condition, a big gap exists between optimal care available and actual care delivered in health care activities.

**Objectives:** There is a lack of clinical education and diagnostic training in BPD and a culture of stigma towards the patients with BPD. The objective is to make an effort to overcome the treatment barriers.

**Methods:** All the effective treatments with empirical confirmation of their efficacy require 12 to 18 months of weekly or twice weekly sessions. The symposium highlights the description of these treatments particularly dialectical behavioural therapy; mentalization based therapy and transference focused therapy.

**Results:** Polypharmacy regime use derives from the misdiagnosis of BPD as bipolar disorder as well as to target specific BPD symptoms. BPD requires treatment with a long-term psychotherapeutic approach

**Conclusions:** There are several treatments available to the practicing clinician. The outcome data, direct comparisons, and meta-analyses all suggest few reliable differences between these treatments and that no one treatment is more effective than the other. Treatment research for BPD is relatively impoverished compared with other conditions. What are needed are large-scale, multisite studies.

## Consciousness and the Ethics of Cerebral Organoid Research

Karola Kreitmair  
*University of Wisconsin Madison, USA*

Cerebral organoids (COs) are brain-like structures grown from human stem cells for the purpose of neuroscientific research. The prospect of COs manifesting consciousness has led to discussion of the moral status of COs and consequently the ethical protections they should have in research. I argue that focusing on the question of whether or not COs manifest consciousness is insufficient in determining their moral status, because the degree of moral status conferred through consciousness depends not only on structural features of the consciousness present, but also on the content of the conscious experience. Because COs do not exhibit behavior, the only means for detecting the presence of consciousness in COs is via the neural correlates of consciousness (NCC). However, inference from the NCCs merely provides information about the structural features of an other's conscious state and not about the content. Consequently, we cannot deduce from NCC alone whether a CO meets the requirements for conscious states that are sufficient for bestowing a degree of moral status that demands certain research protections. The upshot, I argue, is that the ethics of research involving COs depends not only on the answers to factual questions regarding the presence of conscious states along with ethical analysis of the moral obligations conferred by such conscious states, but importantly also depends on value judgments about the degree of tolerance we ought to have for error and uncertainty in determining the moral status of COs.

## Making the History of Nazi Medicine relevant for Teaching Medical Ethics Today: Examples from the Düsseldorf Medical School Curriculum

Matthis Krischel  
*Heinrich Heine University Düsseldorf, Germany*

Germany is one of the few countries in which history of medicine and medical ethics are obligatory elements of the medical school curriculum. This is, of course, to a large part due to the history of Nazi medical crimes, committed by German physicians and bio-scientists. Usually, a single department's members teach history of medicine and medical ethics, creating opportunities to integrate the two approaches to reflecting medicine.

In this contribution, I will present examples from the Düsseldorf medical school curriculum (history of human subject research ethics, history of psychiatry, allocation of scarce resources, ethics at the beginning of life, ethics at the end of life, moral resilience) and show how historical experiences can be made relevant for medical ethics education today.

## The Gift of Death and Dying

Nicholas Krejchi  
*University of Texas Rio Grande Valley, USA*

Death looms in the dark spaces of our minds and often invites anxiety when it enters our central consciousness. It is life's only certainty and yet remains shrouded in the mystery of the unknown as no man has ever traversed the river Styx and returned to tell the tale. In 15 minutes, I hope to embrace death's enigmatic nature through ontological investigation and reframe the way we see this old foe. We will go on a walk along the Nile River, into the audience of an Athenian courtroom and beyond "the horror of the shade". We will grapple with rationality, grief, death, and ultimately reemerge with a renewed appreciation for the beauty of life as it relates to our mortality.

## Principles of Bioethics in UNESCO's "Universal Declaration on Bioethics and Human Rights" (2005)

Mitsuyasu Kurosu  
*Tokyo Medical University, Japan*

The "Universal Declaration on Bioethics and Human Rights" was adopted in 2005 by UNESCO. The Declaration has 15 articles of bioethics principles. Characteristic of the Declaration are superiority of human dignity and human rights, protection of patients and subjects, respect for community, society and nation and public interest to human beings. Fifteen years have passed since 2005, and advances in technology have led to the development of genomic medicine, regenerative medicine, telemedicine and so on. Then it should be emphasized that human beings are essentially vulnerable and supporting autonomy of person is important. And dead person should be also mentioned from viewpoints of genetics and personal health care information. On the other hand, the survival of human beings and living organisms is threatened by climate change by global warming and microplastic pollution and so on. Therefore, it is necessary to add preventive principles and to emphasize future generation in the current principles. By the way, is it possible that all principles are satisfied at the same time? I think it is not possible and then we should only continue to discuss what is best interest of a person, family, community, nation or human beings.

## Coexistence of Equality and Utility Principles for Resource Allocation Decision-making in an Increasing Niche Orphan Biologics Market. An Ethical Conundrum for Decision-Makers

Teresa Barcina Lacosta  
CEU San Pablo University, Spain

Following the increasing development of the "Global Orphan Drug Market", healthcare providers in charge of resource allocation have been facing challenging decision-making processes regarding pricing and reimbursement (P & R) of exceptionally costly innovative pharmaceuticals. Along the intricate P&R journey, issues of timely and affordable access to treatment are often left unaddressed.

This study focuses on orphan biologics and sets the ERT (enzyme replacement therapy) case for Gaucher's disease as an example to evidence how the principles of equality and utility maximization get confronted within a decision-making context.

On the one hand, the elevated price of orphan drugs and the reduced number of patients that can be potentially benefited, turn the objective of maximizing utility into a complicated task. On the other hand, exclusively applying utility maximization strategies leads to important inequalities in the provision of care within the society, being the perpetuation of these inequalities a matter of public health dimensions to be addressed.

Based on the argument that a balance between both principles can be found while using value for money demonstration methodologies for resource allocation, this paper signals the need to apply rational and transparent criteria along the whole health technology assessment process.

## Ethics and the New Era of Genetics

Beáta Laki  
University of Pécs, Hungary

These days one of the most difficult moral issues in science is the use of genetic engineering technology to treat, prevent diseases on somatic and on germline levels (and here we didn't mention the enhancement opportunities). Analyzing this field, we already faced many arguments in favor of and against a few of them. But it is not just a theoretical issue anymore thanks to the fast developing science. That is the reason why we have to be aware of the possible and real consequences of them. In my presentation I put in the center of the interest the ethical interpretation of the recommendation of the International Commission in the Clinical Use of Human Germline Genome Editing. The document focuses on mostly technical, methodical issues but not on ethical ones. Not just from my point of view but according to the authors it is necessary to deal with this kind of questions. My aim is to highlight the moral perspective of germline gene editing technology and to collect the pros and counterarguments related to these highly controversial interventions.

## Using an Implementation Research Tool to Guide the Implementation of Non-Invasive Prenatal Screening

Tierry M. Laforce, Vardit Ravitsky, Anne-Marie Laberge  
Université de Montréal, Canada

cffDNA screening has changed the landscape of prenatal screening. In Canada, 3 provinces and 1 territory are covering its cost through medicare for women with a high chance of having a fetus with trisomy 21. Yet, various stakeholders are calling for universal coverage, not only for trisomy 21, but rather an expanded list of genetic conditions.

This presentation will focus on the normative evaluation of the implementation of cffDNA screening. Using research translation as a theoretical framework, we argue that it is being implemented as a novel intervention. It needs to be evaluated accordingly before it moves forward. To do so, we are applying the Consolidated Framework for implementation Research (CFIR) to the implementation of cffDNA screening in the Canadian context as a case study. The CFIR is a validated tool used to evaluate contextual factors for a successful implementation of an intervention. It has never been applied to cffDNA screening. We argue that its strength resides in its ability to identify barriers and facilitators to implementation preemptively.

This work will help decision-makers select the strategy most likely to be successful with data emerging from stakeholders.

## Do we need "Precision Medicine Ethics"?

Teodora Lalova<sup>1</sup>, Isabelle Huys<sup>1</sup>, Peggy Valcke, Anastasia Negrouk<sup>2</sup>,  
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Precision medicine (PM) is regarded as profoundly more data-intensive in comparison to conventional forms of medicine. In Canada, Beauvais & Knoppers claim that establishing a learning health care system (LHS) that supports a data flow from research to the clinics and from the clinics back to research is the way forward for achieving PM in practice. However, when it comes to research ethics, the international paradigm relies on the sharp distinction between research and clinical practice. An LHS ethical framework for the US context has been previously proposed by Faden et al. Furthermore, the concept of LHS has been investigated from numerous theoretical sides, again mainly in relation to the US regulatory system. The goal of this presentation is to position on European soil the debate on precision medicine, LHS and the potential need to re-think professional research ethical standards. The authors aim to look at current legal and ethical European scholarship that addresses the issues presented above (such as works by Vayena, Blassime, Budrionis, Wouters), and to establish a link with the relevant research conducted at the other side of the Atlantic.



## Uterus Transplants in Europe: Ethical and Regulatory Implications

Martyna Laszewska-Hellriegel<sup>1</sup>, Agnieszka Bielska-Brodziak<sup>2</sup>

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March 2019 was an important date for uterus transplantations in Europe. Another baby was born from a transplanted uterus, this time in Germany. The first steps of European Uterus transplants were taken in Sweden in 2014 where already 14 babies have been born. This way, uterus transplantation is becoming a treatment possibility for women suffering from uterine factor infertility. This form of infertility statistically accounts for three per cent of all infertility in women. Uterus transplant permits women, who until now could choose between surrogacy or adoption, to experience their own pregnancy and give birth to their own genetic related child. Unfortunately, uterus transplantation brings a substantial risk both to donors and recipients compared with other organ transplants. Therefore, it is more difficult to justify. Also, the purpose of the operation is much different: the operation is not about saving the life, but the quality of life and the wish of having a child. The first point of the oral presentation are the ethical risks and benefits of uterus transplantation for the three parties involved in this process (a donor, a recipient and a possible child). The second point are the regulatory possibilities regarding a uterus transplant, especially the crucial problem - who should pay for it?

## Ethical and Legal Issues of Tele-palliative Care: Perspectives from Home Palliative Care Teams

See Muah Lee<sup>1,2</sup>, Poh Heng Chong<sup>3</sup>, Norhisham Main<sup>1</sup>

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<sup>3</sup>HCA Home Hospice, Singapore

**Introduction:** Patients requiring end of life care are often managed in the institutions or by home visits from the home palliative care teams. This is labor intensive, with limitations in efficiency and reach especially for countries like Singapore, with a rapidly ageing population, many of whom may experience prolonged phase of dying due to chronic diseases and frailty. Tele-palliative care, conducted through the audio-visual media using telecommunication technology, blended with home visits is an alternative. For selected patients who consent, this may also help facilitate dying at home.

**Issues:** The home palliative care teams working in HCA Home Hospice have concerns over privacy, body image representations in recordings and voluntariness of patient and care consent. The human connection and the touch that assuages skin hunger in this vulnerable group will also have to be substituted by a new mode of techno-intimacy. Tele-palliative care inherently precludes physical examination. This can lead to inadequate assessment, treatment of pain or acute complications such as cord compression, causing prolonged suffering, resulting in allegations of negligence.

The audio-visual recording of tele-palliative care also has statutory obligations related to data access, storage and protection.

**Management:** Policies, training and safeguards must be emplaced to manage these issues.

## Risk of Premature Death in Injured of the Lower Limb: A Legal Issue?

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Despite the vast literature on the risk of premature death (RPD) due to physical inactivity and its scientific-statistical robustness or due to the strong correlation between epidemiological and pathophysiological data, there are not many specific studies on the analysis of this risk in severe injuries of lower limbs or in individuals whose gait perimeter is suddenly reduced (with increased sedentary lifestyle) due to an "external" cause. Thus, it is intended in this project, to analyze the effective existence of this RMP, through a selective and comparative analysis of the MedLeg Database (INMLCF) and the data obtained through the National Register of Deaths (SICO), since the beginning of its use (2004), until 2015. Subsequent comparison will be made with standardized population data obtained from Portugal Statistics Institute (INE), regarding the portuguese mortality between 18-65 years and the search for a possible "dose response" effect, regarding the degree of disability and mortality. Once this RPD is proved, given that the fact this pathophysiology is widely known, is intended to build a predictive table of this risk, which allows the Judicial System to adequately and accurately compensate these injured victims, through the legal component included in "Future Damage".

## A New Form for the Free and Informed Consent Terms Used in a Reference Hospital of High Complexity in Brazil

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Bioethical principles are increasingly nuclear and essential in health care. The Free and Informed Consent Terms (FICT) form informs patients and their families of the possible interventions, risks and benefits, allowing them to be fully aware and to participate in the decisions on the treatment.

The FICT form must also legally protect the institution and their professionals from unreasonable and unjust legal demands made a posteriori by the patient.

This work analyzed 82 models of FICT used in the different medical areas (surgery, anesthesia, diagnosis, ICT, etc.) of a reference hospital of high-complexity in Brazil.

The analysis of such FICTs showed that there was a greater concern with professional and institutional safeguard, than in providing complete and clear information to the patient.

This study resulted in the elaboration, validation and adoption of a new standard FICT used in all the areas of the institution. It is believed that the newly adopted FICT yields a better balance between the provision of the necessary information to the patient and his family, and the legal protection of the professionals and the institution involved in the health care. The new FICT form is freely available contacting the first author of this paper.



## Comparative Study between Bulgarian and Foreign Medical Students Regarding Medical Ethics Education

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Medical ethics and bioethics are a subject studied during the first academic year in the Faculty of Medicine in Medical University of Sofia in Bulgaria to both Bulgarian and foreign students. Future physician having a medical ethics and bioethics education is better equipped to deal with ethical challenges appeared in medical practice. The purpose of this study is the comparative analysis between Bulgarian and foreign medical students regarding medical ethics and bioethics education after the end of the respective course. A paper questionnaire was developed, structured in four sections. The questionnaire is focused on medical students' opinion about the application of the principles of medical ethics and bioethics into their future work. Also, further questions asked to the participants about their demographic characteristics, and the preferred teaching methods, during the course. Two conclusions can be made after the analysis of data collected. First conclusion is on how students evaluate the course as a tool to improve their professionalism and second conclusion is regarding the preferred teaching methods, among Bulgarian students and students from other countries.

## The Case of Inmate Physicians as a Subject in the Teaching of Medical Ethics and Beyond

Astrid Ley  
Sachsenhausen Memorial and Museum, Germany

Inmate physicians were doctors who had been deported to concentration camps and assigned to work in medical facilities there. Like other inmate officials, they were granted somewhat greater freedom of action and privileges that helped them to survive. Still, they were in an inherently difficult position, having to maintain a constant balancing act between obeying the commands of the SS and safeguarding the interests of their patients. Strictly speaking, they could not serve as doctors in the camps without violating the principles of medical ethics.

Aside from that: Jewish and non-Jewish inmate physicians – as well as German and non-German or West- and East-European prisoners – occupied different positions in the SS-made prisoners' hierarchy. As a result, their living and working conditions in the camps differed, not the least with regard to the scope for action available and the privileges granted to them.

Due to its complexity, the case of inmate physicians is relevant not just in debates on medical ethics. It also provides general insights into concentration camp history, SS rule and the internal structure of the so-called "inmate society". At Sachsenhausen memorial, we therefore use the topic both in professional training for medics and in general education programs for students.

## Primary Decompressive Craniectomy: Decision Supported by Evidence or Overtreatment: The Ethics of Withholding this Operative Endeavor

Leon Levi, Dana Peso, Moni Benifla, Vladimir Shapira, Josef Benari, Eugenia Mahamid, Marius Constantinescu, Gill Sviri  
Rambam Medical Center, Israel

We compared actual-outcome of immediate decompressive-craniectomy (DCP) for mass lesion evacuation in anticipation of reasonable outcome. The premorbid status and patient'/family perceptions are obscure. Two prognostic-scores were used to define where ethical considerations help the neurosurgeon deciding about treatment that might lead to miserable outcome.

272 DCP over 1999-2018 with their calculated risk by CRASH-2 and IMPACT methodology. 15 were lost to 1-y post-injury time point. The dataset contains demographics, pre-injury status, trauma details and process of care/timing until the last available follow-up.

47 were younger than 16, 179 adults and 46 elderly. 24.2% gained 6-month-favorable outcome with slight increase to 28% in 1-year. The 6-month prediction of unfavorable-outcome by IMPACT and CRASH-2 calculator were above the actual outcome in less severe risk band (n=69). Age is the major effector in the higher risk band (above 50% chance of unfavorable outcome n=203).

In severe TBI in need of immediate DCP (within 4 hours of injury) the traditional prognostic scores were over pessimistic at the 50% chance of unfavorable-6-month-outcome, thus mandating careful recording of the decision for unconscious patients in the high-risk group about their dismal future. Very few of the elderly gained functional outcome by this immediate procedure.

## When Right to Food Stands in Conflict with Access to Food Restrictions Required to Manage Genetically Determined Hyperphagia: The Trouble with Prader-Willi Syndrome Under the UN CRPD

Maria Libura  
University of Warmia and Mazury in Olsztyn, Poland

Under the UN Convention on the Rights of Persons with Disabilities (UN CRPD) access to food is construed as a human right issue. The perspective of UN CRPD focuses on the danger of malnutrition, which may stem from impaired capacity, lack of support to prepare food or eat, lack of adequate income, lack of transportation or other help to obtain food, being unable to enter and use public eating establishments, or feeling unwelcome in public situations involving food (cafés, restaurants, public celebrations and events) (Webber et al., 2007). There is however a rare disability associated with Prader-Willi Syndrome that manifests itself as uncontrollable hyperphagia. Persons with this syndrome require close monitoring of their food and caloric intake as they lack the satiety signal, most likely due to an inborn dysregulation of the hypothalamus. Otherwise, they develop morbid obesity, leading to life-threatening medical symptoms and a premature death. This rare disability poses numerous ethical, legal and practical problems in day-to-day management, which cannot be easily accommodated under the UN CRPD. The paper will address the ethical and legal dilemmas facing carers in selected EU countries.

## A Comparative Analysis of Gender Expectations in Gamete Donors

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The use of donated gametes for reproductive purpose is a growing issue in Buenos Aires fertility clinics. In 2015, Argentina performed the 23.7% of all ART treatment carried out in Latin America and recorded by the RedLara Register, while Brazil contributed with 41.5% and Mexico with 13.7%. This technoscientific reality was accompanied by important changes at the regulatory level. The Law of Equal Marriage (2010), the Law of Medically Assisted Reproduction (2013), and the introduction of assisted reproductive techniques as third filial source (2015) were approved. Yet, despite the advances recorded in this medical-scientific reality, gender expectations still guide professional practice. During the last years, the increase of gamete (particularly egg) donation in Argentina might be understood as a consequence of the growing inequities resulting from the current socio-political crisis regardless of the efforts to 'altruistize' donor gametes. This study will compare egg and sperm donor's expectations considering three levels: a) institutional practices; b) body taming; and c) anonymity. The questions that lead the analysis are: how do gender expectations frame the practice of gamete donation? How do notions of procreation, kinship and propagation influence and/or determine the ways of managing reproductive cells?

## Access to Healthcare for the Immigrant Population is an Ethical Minimum

Sandra Lopes Aparício, Manuela Resende, Rui Nunes  
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International migratory flows have impelled host societies to formulate and promote policies that target ethnic and cultural minorities.

Since the beginning of the 2000s, Portugal has witnessed an intensification of Chinese migratory flows, as a consequence of new laws to regulate immigrants and the passage of Macau's sovereignty to China in 1999. The population of Chinese origin increased from 3,278, in the year 2000, to 25,357 in 2018, currently representing the 6th largest community of foreign origin residing in Portugal.

However, the visibility of this community, as a user, in the National Health Service (SNS) is low compared to immigrant communities with less national representation. In order to promote justice and equity in the access of this population to health care provided in the NHS, it is essential to formulate and develop policies that positively discriminate against this community.

With the elaboration of this work we intend to reflect on the factors that condition the access of the population of Chinese origin residing in Portugal to health care and to identify measures that promote the pursuit for that same care, ensuring compliance with article 64 of the Constitution of the Portuguese Republic that guarantees everyone the "right to health protection".

## The Human Rights Framework Concerning Assisted Dying

Sien Loos

University of Antwerp, Belgium

Due to the controversial nature of end-of-life interventions such as assisted suicide, the national regulatory frameworks vary from an absolute ban to fully embracing the practice of assisting patients in terminating their lives. In a time where large numbers of people are travelling abroad to receive medical treatment, the wide variety of approaches towards assisted suicide in Europe raises the question as to what legal challenges arise when European citizens want to travel to another European country to be assisted in dying. A particularly important challenge is related to the human rights framework concerning assisted dying. Countries that take a restrictive stance towards assisted suicide emphasize the 'absolute' nature of the right to life, whereas states that exhibit a more permissive regime put more emphasis on the right to private life, as including in particular the right to self-determination at the end of life. In light of this divide, my presentation aims at clarifying the human rights principles that have to be complied with when regulating assisted suicide in either a restrictive or permissive way. Special attention will be paid to the margin of appreciation awarded by the European Court of Human Rights.

## Bioethical Issues in the Care of Patients Affected by Rare Diseases

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Rare diseases have particular characteristics: they are less frequent than common diseases, medical knowledge about them is scarcer, the vast majority are of genetic origin, there is usually a significant delay in diagnosis, therapeutic options are scarce, they are usually chronic and disabling and sometimes reduce life expectancy significantly, affected people feel social abandonment and isolation, there is little scientific evidence and little research on them. These particular characteristics give rise to the fact that in the care of patients with rare diseases certain bioethical issues occur more frequently: the risk of negative or positive discrimination of the affected patients, issues related to their referral to centers of experience, issues related to genetic advice, the responsibility of considering these diseases in the daily clinical practice and the responsibility of gathering experience and researching on them as far as possible, issues in the prescription of adequate treatments due to the limited available experience with them and their frequent excessively high cost, the need for a multidisciplinary approach and, finally in some cases, issues related to palliative care and the adequacy of therapeutic effort.

## CPME Policy on Artificial Intelligence (AI) in Health Care

Christian Lovis  
The Geneva University Hospitals, Switzerland

On 16 November 2019, the CPME Board adopted the 'CPME Policy on AI in Health Care' (CPME 2019/062 FINAL).

The Standing Committee of European Doctors (CPME) represents national medical associations across Europe. We are committed to contributing the medical profession's point of view to EU and European policy-making through pro-active cooperation on a wide range of health and healthcare related issues.

Policy Summary: AI has a potential to transform health care delivery by facilitating equal access to efficient treatment and enhancing accuracy of diagnosis and the workflow of physicians.

To convert this potential into reality, CPME advocates the development of health care AI that is based on robust evidences; its use must be accountable, non-discriminatory and respect patients' privacy. The safe use of health care AI and understanding of its advantages and limitations should be part of basic medical education and continuing medical education. Additional regulatory steps are needed to adapt intellectual property, liability, privacy and governance regimes.

CPME recognizes the efforts made by the EU on AI so far. However, CPME calls on the European Commission to put greater emphasis on trustability and safety of AI applications in health care and to better engage health care professionals in its work.

## Bioethics of Disability

Theong Low  
IIOPM - Melbourne, Australia

The issue of Bioethics of the disable centres on the rights of a person with disability. Continuing conflicts exist between mainstream bioethics and advocates of disability rights movement. The question of how severely disable a person or a foetus has to be before it is morally acceptable to allow them to be kill / let die / or be aborted will be discussed, and is it morally acceptable to withhold treatment in a disable person to preserve limited resources.

With the rapidly advancing medical technologies and the increasing use of Non-Invasive Prenatal Testing (NIPT), should health professionals be required to advice on the issue of terminations when an unexpected abnormality is detected? And is this leading to the practice of Eugenics by default? And with advancing use of prenatal DNA sequencing, does this lead to a future of sex selection and designer babies.

Even if we can terminate all unborn with a disability, we would still be unable to totally eliminate disabilities as we will then have to focus on acquired disabilities.

In a world where discrimination against another human on the basis of sex, race, religion, sexual orientation is taboo, is it still justifiable to discriminate against the disable?

## Ethical Dilemmas of Second Stage Commission on Artificial Pregnancy Termination

Adolf Lukanovic  
University Medical Centre Ljubljana, Slovenia

The most important decision in life is certainly the decision about becoming a parent. It is a fundamental human right and enables individuals and couples to produce the desired number of offspring over a time period of their choice, by using contraception and treating infertility.

The right to artificial pregnancy termination should not be taken for granted. European countries have different attitudes, traditions and laws in such regard. The fundamental conflict involved therewith is the right to freely dispose of one's body on the one hand and the right to life on the other. Both rights are guaranteed by the European Convention on Human Rights, namely Article 8 on the right to respect for private and family life and Article 2 on the right to life. Some lawyers interpret the constitutionally guaranteed right to privacy on such a broad scale that they claim it allows a woman the right to make independent reproductive choices without the intervention of the state, i.e., to decide to terminate her pregnancy. It can be concluded that the European Convention on Human Rights has not yet taken a final stand regarding the definition of the right to life.

## Can Patient Information Held by an AI Robot be Protected by the Duty of Confidentiality

Michael Lupton  
Bond University, Australia

Modern medicine is today driven by scientific discoveries in fields such as genetics, stem cells and CRISPR CAS 9. The implementation of these technologies in the form of therapeutic treatment is still carried out by doctors in accordance with the moral rules they swear to uphold in the Hippocratic Oath. The doctor patient relationship remains a contractual one, based on the moral precepts of the Oath, a part of which is the duty of confidentiality. Modern technology in the shape of AI robots has impacted on the field of medicine and thus the duty of confidentiality as well. AI platforms run by algorithms, such as IBM's Watson, are now being used in diagnosis to drive down costs eg. the use of automated diagnosis to pinpoint diabetic retinopathy by subjecting retinal images to robotic scrutiny. Robots are widely used to read X Rays as well. In both fields they are matched and bettered the results of human doctors. From a legal and ethical point of view it is important to note that the patient's symptoms were obtained by the AI robot 'interviewing' the patient or by a human doctor feeding the patient's data into the robot. The net result is that the robot is now in possession of sensitive patient information. Because the robot is not a 'person' in the legal sense of the word, it does not have 'moral instincts to guide it and thus to treat the information in terms of the confidentiality imprimatur of a human doctor who is bound by the Hippocratic Oath. Alternative solutions.

## Discussion on Personal Privacy of Doctors under the Background of Internet Medical Treatment

Suyuan Ma  
Guangzhou University of Traditional Chinese Medicine School of Marxism, China

Under the background of "Internet +" era, the Internet medical platform, as the product of the integration of the Internet and the medical industry, brings convenient medical treatment conditions to patients, but at the same time, there is also the risk of doctors' personal information disclosure. This paper discusses the issue of personal privacy of doctors on the Internet medical platform from the aspects of data protection and privacy, laws and regulations, social norms, etc., and puts forward suggestions for standardizing medical services and safeguarding the rights and interests of personal privacy of doctors.

## Article 8 of the ECHR, Human Dignity and the Disposal of the Human Body and its Parts

Neil Maddox  
Maynooth University, Ireland

In recent years, there has been numerous scandals in the UK and beyond, about the failure of medical authorities and medical waste disposal companies to properly dispose of the human remains of the dead, as well as body-parts and tissue from the still-living. This paper examines the cause of this regulatory failure by examining the adequacy of existing legal frameworks to deal with the problem. I find systems of regulation that have as their basis autonomy and consent are inadequate to prevent future misuse of disposed human biomaterials, once an initial consent to their disposal has been given. In addition, property models of the body can lead to inappropriate valuations of it. I contend that human dignity is not a vacuous concept and can be useful where autonomy and property models fail. While the substantive meaning of dignity is highly contested, it may be used as interpretative principle to assist the further explication of the catalogue of human rights generated through the lens of dignity. In this context, I explore the possibilities of Article 8 of the ECHR being used in the future to set legal guidelines through a rights-based approach to deal with regulating the disposal of human bodies and their parts.

## Withholding and Withdrawing Life Support Measures from Terminally Ill Patients: Perceptions of Healthcare Workers at Bugando Medical Centre, Mwanza Region-Tanzania

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**Background:** Withholding and withdrawing life support measures from terminally ill patients are challenges in clinical practice, particularly in the ICU; it brought different opinions among healthcare workers and still there is no consensus on this practice. However, in some countries there are guidelines that help and support clinicians in making decisions of withholding and withdrawing life support measures from terminally ill patients. In Tanzania, there is neither guideline nor legal frameworks governing the practices; these subject healthcare workers into serious ethical dilemmas in end-of-life decisions making.

**Objectives:** To explore the perceptions of healthcare workers on withholding and withdrawing life supportive measures from terminally ill patients at Bugando Medical Centre, Mwanza region-Tanzania.

**Methods:** A qualitative descriptive (QD) study was used to assess perceptions of healthcare workers regarding withdrawing and withholding life support from terminally ill patients in the ICU. In depth interviews were used to collect information from thirteen participants using a semi structured interview guide. An appointment was made with nurses and physicians depending on their availability. Data were analyzed using qualitative content analysis.

**Results:** A healthcare workers perceptions varies in decisions of withholding and withdrawing life supportive measures from terminally ill patients. However, they face many challenges in making decisions when caring terminally.

## Healthcare Professionals' Wellbeing and Burnout: What Can Help and What Not?

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**Background:** Healthcare professionals dealing with complex and multimorbid patients are exposed to different risks for their wellbeing. So, it is important to look for risk and protective factors.

**Aim:** To detect any within- and between-group differences regarding wellbeing and burnout in two different medical specializations.

**Method:** Healthcare providers working in palliative care/oncology unit and in rehabilitation medicine was involved in an observational cross-sectional study. We administered an anonymous questionnaire constituted by MASI-R (distress/eustress), MDS-R (moral distress), HECS (ethical climate), MBI-GS (burnout), PANAS (positive and negative emotions), CD-RISC-10 (resilience).

**Results:** 315 healthcare professionals participated (rehabilitation medicine: 70.5%; palliative care/oncology: 29.5%). The palliative care providers reported higher moral distress ( $t(265)=-4.17$ ,  $p.001$ ), but also more positive ethical climate ( $t(307)=-2.97$ ,  $p.01$ ) than colleagues working in rehabilitation medicine. After controlling for the influence of medical specialization and gender through hierarchical regression, negative affect ( $\beta=.66$ ,  $p.001$ ) and moral distress ( $\beta=.09$ ,  $p.05$ ) predicted emotional exhaustion. Moreover, positive affect ( $\beta=.36$ ,  $p.001$ ) and social support ( $\beta=.34$ ,  $p.001$ ) increased wellbeing and negative affect reduced it ( $\beta=-.25$ ,  $p.001$ ).

**Conclusions:** Mapping resources and risk factors may allow customizing interventions for the healthcare professionals.



## Developing a New Code of Conduct for the Veterinary Profession in Portugal: Insights from a Collaborative Study

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The Portuguese Veterinary Order (Ordem dos Medicos Veterinarios, OMV) was established in 1991 and is the organization responsible for regulating the veterinary profession in Portugal. In order to practise, all veterinarians must be registered with the OMV, abide to its statutes (Law 125/2015, Sept. 3rd) and to the Code of Professional Conduct (Codigo Deontológico, CD-OMV). The CD-OMV has remained virtually unchanged since its inception in October 1994. Within the last 25 years, however, the veterinary profession has changed dramatically and the current CD-OMV has not adapted to societal changes regarding the legal and moral status of animals.

In this presentation, the sequential stages for developing a new Code of Conduct for the veterinary profession in Portugal will be described, namely:

- a) a systematic review of the disciplinary complaints against veterinarians (between 2012 and 2015) to identify categories of offense.
- b) a three round Policy Delphi study with forty-one veterinarians that aimed to explore some of the previous findings in further detail.
- c) a consultation process, open to all OMV members, concerning an earlier draft of the CD-OMV.
- d) the collaborative drafting of the definitive, fit for purpose, version of the CD-OMV, based upon comments and suggestions from the consultation process.

## Illegitimate Limits on Conscientious Objection to Abortion

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In the event of a request for an abortion, it is possible to raise conscientious objection. However, some laws require registration in special registers and mandatory time limits for communicating such a condition which makes the legal nature of the objection conditional. This seriously affects the right to conscientious objection, which cannot be adjusted to predetermines requirements, since it does not exist in the abstract but in the case of specific cases.

Conscientious objection in the field of health is the fundamental right of health professionals to refuse to conduct a specific behavior based on a legal duty, for violating intimate moral or religious convictions. The infringement of this right would not only violate freedom of conscience or religion but also the right to free development of personality.

Demand from the objector an action contrary to his conviction, infringes the fundamental right to free expression of conscience, and would imply an attack on his own dignity, since it would be thus reduced to a mere instrument of the will of third parties that invoke a right that does not have such fundamental character.

This would prevent the free expression of one's conscience in order to give rise to coercion.

## Nurse on Nurse Bullying: Screening Failures and Hospital Liability

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Nurses have a long and sordid history of bullying. For all the wonderful things that Florence Nightingale did to elevate Nursing to a profession, the Notes on Nursing (1859) included expected behaviors of nurses both on and off the job that were essentially codified bullying. It was not until the early 1980s that bullying in the Nursing profession began to be systematically studied. In this regard, links to the women's movement cannot and should not be discounted. These early studies looked at physician (male) bullying of nurses (female) and then rather quickly shifted to nurse on nurse (female on female or female on male) encounters. The phrase "nurses eat their young" pertaining to nurse on nurse bullying was first attributed to Dr. JE Meissner in an academic paper published in Nursing, March 1986, 16 (3) 51-3. That phrase has become a catchall in the Nursing profession as the one answer that fits all dysfunctional organizational, interpersonal, and clinical situations throughout the world. Various research studies undertaken in the early 2000s and continuing until recently identified nurses as an oppressed work group likely due to a perceived lack of power in the health care system (Dong and Temple). This condition (nurse as victim) was used to shift the etiology of the bullying problem from individual aberrations of personality and behavior to that of organizational structure and behavior. Solutions are suggested to this problem that effects over 90% of nurses.

## Dealing with a Minor's Ethical and Medical Dilemma That Demand not Reporting her Parents about her Abortion and Making Decision According to the Seven-Step Model

Helen Malka-Zeevi, Masad Barhoum  
Galilee Medical Center, Israel

Hospital staff, physician and nurses has always faced today as previously with ethical and professional dilemmas during their work. The need to resolve ethical dilemmas is critical for them especially when they must decide in complex and total uncertainty situations, if the determined decision is correct, appropriate or the least harmful.

The dilemma is whether to continue abortion of a 17 year-old Muslim minor that requires a written inform consent of her parents but she refuse sharing them because she is afraid for her life, and show the way of making an ethical decision in hospital according to seven steps model.

The two conflict values: life and autonomy of the minor and facing the parents' rights to know about their child and give inform consent.

This work will present the minors' place in making decisions relating to her health according to Israeli law. In order to make a decision in the minors' matter, we will examine whether it is a moral or a legal dilemma, and the possibilities that the medical staff coping with and choosing one path when the existing law does not give one solution to the unique ethical issue according to this minor that now at our hospital.



## Experience of Organ Donation Drive in Urban India

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Organ donation rate of India is 0.26 per million which is one of the lowest in the world compared to 26 per million in the US and 36 per million in Spain. These numbers highlight the significance of organ donation. Many illegal ways of organ donations and violation of bioethical principals has been reported.

Women Doctor's Wing (WDW) of Indian Medical Association (IMA), Pimpri Chinchwad Bhosari (PCB) from Maharashtra state of Western part of INDIA had taken an initiative to create awareness sessions in the community to protect bioethical principals in organ donation.

The information booklets in English and local (Marathi language) distributed, pictorial posters about organ donation displayed. Organ donation pledge forms were distributed after question answer session. Organ Donor Card was given to them which is connected to zonal and National Organ and Tissue Transplant Organization of India.

Total 15 Awareness programs conducted in college, residential societies, senior citizen clubs, etc, in which total 1210 people attended and 168 organ donation pledge forms received voluntarily.

Increasing awareness can help to solve bioethical issues about organ donation. It will be helpful to increase the percentage of organ donation in India.

## Study to Assess the Level of Awareness Regarding Biomedical Waste Management among Doctors

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**Background:** In modern era, increasing number of healthcare centers leads to increasing number of biomedical wastes. Biomedical waste which is the product of healthcare activities causes serious environmental hazard.

**Objective:** 1. To assess the level of awareness regarding biomedical waste management among doctors. 2. To study the association between level of awareness of biomedical waste management and demographical factor.

**Methods and Materials:** A cross sectional study conducted using pretested questionnaire specially designed for this purpose. Total 200 doctors participated in the study from Malaysia and India. Self-administer questionnaire distributed through online.

**Results:** Total 200 doctors were included in study, out of which 156(78%) were from India and 44(22%) were from Malaysia. Indian doctors (92.31%) show higher awareness on biomedical waste management compared to Malaysian doctors (90.91%) however the difference was statistically not significant (P value- 0.7626, Odds ratio-1.200, 95% CI- 0.3669-3.924).

**Conclusion:** Lack of awareness and knowledge regarding biomedical waste management and lack of supervision on biomedical waste management can cause environmental hazard. Considering environmental hazard, biomedical waste management requires increasing awareness among doctors.

## Global Health Ethics: A Study on Self-Experimentation in Emergency Contexts

Tania Manríquez Roa, Nikola Biller-Andorno

University of Zurich, Switzerland

Scientists around the world have been conducting experiments on themselves to develop a vaccine against Covid-19. Self-experimentation is currently in a grey zone – it is not addressed directly in key research ethics regulations, including the Declaration of Helsinki, and its legal status is often unclear. Some self-experimenters claim they might develop an open-source vaccine against Covid-19 that could benefit populations that still largely lack access to vaccines.

We are conducting an exploratory study that aims to contribute to the debate on ethical research during health emergencies. We will gather the views of a panel of 15 experts in self-experimentation, including self-experimenters, policymakers, scholars, and members of research ethics committees and regulatory agencies of medical products. We will collect the main arguments on whether self-experimentation should be allowed in emergency contexts and if so, under what conditions. We seek to identify the continuum of perspectives on self-experimentation and explore points of convergence concerning two interests in conflict: the urge to develop vaccines or medicines that are easily accessible, and the fulfilment of standard research regulations and requirements of institutional review boards. We will address the issues of public trust, responsibility, solidarity, safety, efficacy, and the role of ethical committees and regulatory agencies.

## End-of-life Care to Patients with Advanced Dementia in Emergency Situations in Acute Hospitals: Clinical and Ethical Aspects

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Patients with advanced dementia are commonly hospitalized in acute care wards, yet there is limited data regarding the end-of-life care delivered to this population. This study included 315 healthcare providers (190 from medical and 125 from surgical wards), 159 physicians and 156 nurses working in two hospitals. Participants were given two hypothetical case scenarios of people with advanced dementia who presented to the emergency room with acute gastrointestinal bleeding (AGB) or aspiration pneumonia with respiratory failure (APRF). The respondents indicated their preferred interventions. Interventions chosen for AGB were blood tests (84.1%), intravenous fluids (79.6%), blood and blood products (68.5%), nasogastric tube (67.9%), analgesia (50%); central venous catheter (41.9%), emergency gastroscopy (41.6%), and subcutaneous fluid infusion (21.3%). Interventions chosen for APRF were intravenous fluids (72.7%), antibiotics (72.4%), blood tests (69.8%), analgesia (62.2%), sedation (58.4%), and intubation and mechanical ventilation (37.2%). Only 50-60% of respondents gave analgesia or sedation, and many performed invasive procedures such as gastroscopy or intubation. Healthcare providers consider blood transfusions and antibiotics as "basic" and part of palliative care, since those interventions may decrease suffering and fatigue. There is a need for training healthcare professionals working at acute hospitals regarding end-of-life care for patients with advanced dementia.

## Bioethics: The Core of Research Education for Medical Students

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Even though research is the basis of evidence-based medicine, we have found that it is not being addressed sufficiently within medical education. Therefore, the International Federation of International Federation of Medical Students' Associations (IFMSA) designed a Basic Research Competencies Framework, emphasizing a special need for ethics within undergraduate education.

A group of IFMSA members, both medical students and recent graduates, assessed medical student's need for research education after evaluating responses from a previous survey to provide a systematic framework for future research education.

We have identified six overarching competencies we envision as mandatory including Values as a core competency. Whereas Values consist of Safeguards, Bioethics and Good Scientific Practice. Bioethics, for example, can be taught as in teaching basic principles such as non-maleficence, beneficence, autonomy, justice, confidentiality, and truth-telling.

A fundamental understanding of Bioethics should not only play an integral part in every medical student's education but especially within the context of research and evidence-based medicine. With our framework, we want to underline the need for research education in order to perform evidence-based medicine and eventually contribute to the scientific world. We call on all institutions to promote research education and integrate Bioethics within research education for medical students.

## Euthanasia and Assisted Suicide: What is the Role of Psychologists?

Sílvia Marina

University of Porto, Portugal

The political and social debate about euthanasia and/or assisted suicide has been particularly relevant in recent years. Most of the research about the subject is around the conflict of values. Instead, there is little work about the professional role of psychologists in the context of hastening death. In this context we aimed to explore and understand the Psychologists role with people who wish to die. To achieve this goal, we carried out a study to analyze the perceptions of psychologists about their role in the context of hastening death. The opinions of psychologists from different countries were analyzed, in order to create a chart that guide the role of these professionals in this context. Research from psychological science in this field is needed. It is urgent to develop research and create suggestions and guidelines of action for the professional class of psychologists.

## The Italian Bioethical Debate on Assisted Suicide and its Undue Equivalences

Francesca Marin

University of Padua, Italy

On 25 September 2019 Italy's Constitutional Court ruled that anyone who facilitates the implementation of a request for assisted suicide is not punishable if such a request is expressed by a patient who is a) able to make free and conscious decisions, b) is kept alive by life-support treatments and c) is affected by an irreversible pathology that d) causes unbearable physical or psychological pain.

To legitimate this specific form of assisted suicide, the Court invoked the recent Italian law on informed consent (Law no. 219/2017) which recognizes the right to refuse life-sustaining treatment and obtain deep sedation. According to the reasoning of the Court, respecting the patient's will "to let himself die" by withdrawing treatments and refusing the request of a patient in the four aforementioned conditions to be assisted in suicide would amount to discrimination between patients in comparable situations.

Actually, physician-assisted suicide differs from withdrawing treatments and deep palliative sedation with regard to the objectives and procedures. By addressing the differences among these practices, it will be argued that the Court's judgment is based on undue equivalences and seems to confirm and even increase the conceptual ambiguities that still characterize the broader Italian debate on end-of-life issues.

## Understanding Meaning of Non-verbal Language When Teaching and Learning a Second Language

Maxlene Markus-Vider

Haifa University, Israel

When speaking in a language we know, in foreign languages, and when communicating in other international languages, especially English, we must remember the cultural rules and behavior.

Learning a second language develops a hidden language, a non-sound-spoken or written-word language. This non-spoken language is part of an emotional intelligence natural response. It helps express and relate to the language. Understanding nonverbal language assists the teaching and learning experience of the second language. It expresses our immediate response to what we see, feel, hear and understand when learning a second language.

Teachers using emotional intelligence skills to respond to non-verbal reactions have a better understanding of how to add meaning when teaching a second language. Understanding the non-verbal meanings changes the atmosphere in class.

Teaching a second language, while understanding non-verbal expressions and extreme body movements, changes the lesson's pace, making the students understanding more meaningful.

Non-spoken body language conveys the culture and emotions during a second language lesson. The teacher should understand the culture background of the learner when teaching a second language, as an ethical understanding of the learner's needs.

Emotional Intelligence and Bioethics are key to both teaching and learning a second language. They add meaning and support the student and improve the teaching and learning of a second language.

## Multiculturalism Challenges Standardized Ethics

Avrohom Marmorstein  
Hackensack University Medical Center, USA

Some communities within our diverse patient populations have norms which conflict with standard principles of bioethics. In my work as an ordained rabbi, chaplain and bioethicist I see numerous examples within and beyond my own faith community. Standardized systems cherish privacy, but many traditional ethnic groups value tribal unity. Can we give a list of all members of a faith community in the hospital to their community volunteers? Can we ease loneliness by connecting a patient family to others of same background?

Contemporary ethics values equality of gender, but traditional mores favor having personal needs met by someone of the same gender. Discussion of how to provide due respect to the moral principles of healthcare provider and patient.

Hospitals are accustomed to listing patients by religion, and this was an efficient way to categorize spiritual needs. Today there are many people who label themselves as of more than one faith, and mix beliefs and religious practices. Balancing the need to categorize with respect for individual choice. A similar concern exists with listings offering only two choices of gender when patients may not fit in to either.

This presentation will provide creative solutions to some of these problems, give numerous examples and allow healthcare providers to identify such issues and resolve them effectively.

## First Comprehensive Study in Spain about Knowledge and Attitudes of the Public Towards Several Aspects of the Consent System for Organ Procurement

María Victoria Martínez López, David Rodríguez-Arias  
University of Granada, Spain

**Objectives:** To explore the general attitudes of Andalusian citizens towards organ donation and transplantation. In particular: the model of consent for organ procurement, the role of the donor's family and the criteria for determining the death of donors.

**Methods:** The Citizen Panel for Social Research in Andalusia (PACIS) included a sample of 813 people residing in Andalusia aged 18 or over who received a questionnaire by telephone or Internet. The selection was stratified by age group and sex.

**Results:** The majority of people surveyed expressed confidence in the transplant system (93%), and estimated that donating their organs is a duty (78%). 60% believe that the Spanish donation system is transparent. 71% of those are unaware of the presumed consent model and 35% are unaware that families can update the deceased person's preferences regarding organ procurement. The majority (86%) approve of the family acting as a witness or substitute for the deceased's preferences. The majority of the population surveyed consider urgency, longer waiting time, younger age, and difficulty in finding another compatible organ as more important criteria for prioritizing distribution.

**Conclusions:** This study shows mostly positive attitudes towards donation and the transplant system and ignorance regarding the presumed consent system.

## The Holocaust and the Value of the Human Corpse for Bioethics and Human Dignity

Filotheos-Fotios Maroudas  
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The purpose of this essay is to show the direct relevance of dealing with the Jewish corpses made by the Nazis during the Holocaust, to the very value inherent in the human corpse. That the current human corpse management technique - by combustion or composting - seems to serve a new ideology, throughout human history, of managing and dealing with the remnants of our presence on earth, in the logic of a new "final solution" with the dis-solution of what it does not seem to be useful anymore. There is also a connection between the physical / real perpetuation of the identity of the human being compared to the current trend of digital regeneration and storage. Through this original approach of the utterly destructive Nazi choice to exterminate the corpses of the Jews, the importance of giving respect and recognizing human dignity to even "useless", or "vulnerable" populations. The procedure of body rot and skeletal remains are summarized. The identity of the genetic information rescued by the skeleton is then evaluated and the conclusions show the dignity retained by the human corpse in terms of genetic and philosophical aesthetics. In the end, the new bioethical questions that arise in the face of this increasingly prominent practice preferred by those in charge of the Holocaust, namely the extinction of the human body, are raised and analyzed.

## Training in Gender Mainstreaming for Senegalese Bioethicists: Applications of a Sex and Gender Perspective in Research Ethics and Governance

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Scientific evidence has proven that physio-biological, and sociocultural differences between women and men determine their vulnerability to diseases, health-seeking behavior, and response to treatments. Consideration of sex and gender in health research is essential. According to the United Nations Development Program, Senegal struggles to achieve the 5th Sustainable Development Goal targets. In contribution to the achievement of gender equality, a Training Programme in Gender Mainstreaming for scientists affiliated with the Senegalese National Ethics Committee and National Regulatory Authority was conducted. The training was part of the European Union-funded action 'Building Capacities in Gender Mainstreaming for Ethics Committee Members from Senegal to West Africa'. The Programme comprised a hands-on workshop on the incorporation of gendered perspectives into research protocol evaluation, trial site inspection, and the design of gender equality plans. Throughout the programme, the trainees received ongoing mentoring on gender and research ethics, conducted field visits to trial sites in Dakar, and were offered the opportunity to participate in an internship at the Aragón Institutional Review Board (Spain). The training evaluation showed that the trainees largely benefited from the experience, and that their acceptability of applying gendered perspectives in the ethical appraisal of health research design and conduct significantly increased.

## Bioethics Education and the Decision Making of Medical Students

Vera Martins, Miguel Ricou, Cristina Santos, Ivone Duarte  
University of Porto, Portugal

The medical student, as a future health professional responsible for making decisions of the utmost complicity, should be prepared to integrate and relate all acquired knowledge in order to make a decision ethically responsible. This study aims to determine if the teaching of bioethics can influence the decision making of medical students. The MCT xt (Moral Competence Test extended) questionnaire consisting of three ethical dilemmas, was applied to a sample of 4th year medical students from a Faculty of Medicine of Portugal. Most of the students keep the opinion agreeing or disagreeing in the second moment of application of the questionnaire. However, for all students who were neutral at the first moment, most make a decision to disagree or agree with the performance of the dilemma character at the second moment. The results seem to reveal that students after the course of Bioethics have less indecision in their opinion. We believe that education for bioethics is a priority in the secular and pluralistic society in which we live, so the education for Bioethics should be appropriate to the reality, with the development of teaching methodologies that promote the development of the capacity for reflection, critical judgment and the decision-making.

## Solidarity and the Quest for a Cure - Lessons from the LaFora Body Disease Network

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The journey to find a cure for a debilitating and fatal disease, can be an exhilarating one. However, with the advent of augmented intelligent approaches and precision medicine this is often within reach sparking optimism amongst many caregivers and parents of those afflicted. What are the social cohesive forces that operate in synchrony and bind these groups globally towards this common goal? Because the disease is rare, opportunities for research and development of therapeutic drugs are constrained by the asymmetry of profit versus investment for pharmaceutical companies. This paper will discuss three major areas: Firstly, we detail the case of two siblings with a rare form of epilepsy, LaFora body disease and their medical history, currently residing on the island of Eleuthera, in The Bahamas. Secondly, we discuss the challenges of obtaining an orphan drug especially for those who are outside the United States in the context of justice and as it pertains to allocation of resources. Thirdly, we will delve into the abilities for motivated actors to carve a path for hope and cure through solidarity, and global outreach. Indeed, with some luck and serendipity the network has gained traction and support towards the study for a cure. Their commitment has resulted in annual symposiums and a network of support for caregivers and family members. Perhaps it can be a roadmap for those similarly situated.

## Strengthening Frameworks for Post-Ebola Research Ethics Oversight in Liberia

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Ensuring healthy lives and promoting well-being for all is a fundamental Sustainable Development Goal (SDG3). Among countries for which this target is particularly challenging to be achieved by 2030, Liberia deserves special attention. It was hard hit by the unprecedented 2014-2016 Ebola Virus Disease outbreak that reversed some of the health gains which occurred after the end of the 14-year (1989- 2003) civil crisis. These health priorities require a national ethical review system that is able to ensure, guide and catalyze the protection and welfare of research participants.

**Objectives:** 1. To increase the ethics capacity for the oversight of clinical trials in Liberia and recommend the ethics capacity improvement strategy to the Ministry of Health of Liberia for national level implementation.

2. To strengthen the research ethics education, collaboration and ethics harmonization among institutions of the country.

3. To network with West African and European ethics institutions to facilitate the implementation of efficient procedures, standardized guidelines and educative training programs.

**Conclusion:** Building a strong partnership and sharing experiences may likely result in improved health system strengthening, research collaboration and protection of vulnerable populations during health emergency.

**Acknowledgement:** The project is funded by: The European and Developing Countries Clinical Trials Partnership (EDCTP), Grant Number: CSA2018ERC2327-LiberHetica Project

## Ethics and the International Dimension of Organ Trafficking

David Matas

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International law has developed a distinction between organ trafficking and the trafficking of persons for the removal of their organs. The presentation would consider the ethics appropriate to the international dimension of organ trafficking.

The method would be a case study. There is compelling evidence that in China organs are sourced and trafficked from prisoners of conscience killed for their organs. The evidence is such that the United Nations Committee against Torture, the European Parliament, the Czech Parliament, a Canadian Parliamentary subcommittee and the United States Congress House of Representatives have all called for the Government of China to commission or cooperate with an independent investigation into the sourcing of organs in China for transplants.

The presentation would consider, in light of the Chinese experience, the ethical standards already developed by The Transplantation Society, the World Medical Association, the Istanbul Declaration, national transplant societies, the World Health Organization, professional journals and pharmaceutical companies directed to the international dimension of organ trafficking. The conclusion would be that right now ethical standards in this area are underdeveloped and need to be expanded.



## Social Accountability in Health Care Practice: Ignoring the Elephant in the Room

Mary Mathew

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Social Accountability in health care refers to the actions and responsibilities of health care professionals to respond to the health needs of society and be concerned about the long and short term outcomes of their interventions. This practice is vital for equity and improved access to comprehensive health care delivery. In developing countries, providing high-quality health care to large populations is associated with formidable challenges. A literature survey revealed that the provision of effective and timely care is lacking and is compounded by the lack of social accountability, resources, low health care budget and the high rates of worker absenteeism in certain states in India. Social accountability interventions concerning citizen voice and empowerment have been at the forefront in recent times but there seems to be a lack of data regarding health care providers' views and challenges in practicing social accountability. The current attitude towards health care providers in India is one of hostility as evidenced by rising litigations and violence against health care workers. This study aims to map the perceptions and elucidate the challenges faced by health care providers in practicing social accountability and to understand the gaps existing in health care service delivery.

## Fritz Jahr and Bioethics of Sport: Two Distinctive Implications

Matija Mato Škerbić

University of Zagreb, Croatia

Even though Bioethics of Sport was acknowledged as a branch of Philosophy of Sport only recently (MacNamee&Morgan, 2015), it has quickly become one of the most vibrant and important within the field. However, until now it was considered almost only in terms of medicine and biotechnology (Miah, 2016; Camporesi&MacNamee, 2018) covering the range of topics such as doping, gender, disabilities, cyborgization, transhumanism, genetics and sports medicine.

In this paper, I will propose a different perspective within the bioethics of sport, through the bioethical lenses of Fritz Jahr, inventor of bioethics already in 1926 and the first to introduce the name Bioethics (Bio-Ethik). More precisely, I will lean on his 'bioethical imperative' which states: 'respect every living being as an end in itself, and treat it, if possible, as such' (Jahr, 1926) and show two distinctive implications for the philosophy and bio-ethics of sport within two highly neglected areas of animals in sport (Jahr, 1927, 1928), and ecology and environment (Jahr, 1926, 1927).

## Patient Centered Care in Non-cancer Chronic Pain

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**Background:** Chronic pain has a high personal, family and social impact. It has high prevalence (19% in European; 36.7% in Portuguese adults), particularly affecting most vulnerable population (elderly, retired, unemployed and lower educational level).

The majority of chronic pain patients are undertreated and there is no evidence to support pharmacological treatment's efficacy, without any reasonable doubt.

There is no evidence also about the connection between pain intensity and findings in complementary diagnostic tests. Non pharmacological treatment is also many times taken as a "second choice", not much considered.

Communication and person centered approaches can be a key to address this subject and to achieve patient and doctor's satisfaction in chronic pain non-cancer treatment.

**Aim:** Understand non oncologic chronic pain treatment clinical and ethical aspects; identify opportunities of possible approach strategies; transmit person centered approach and doctor-patient communication principles.

**Target group:** Doctors (specialists and trainees) and medical students: each one of them is going to contact with patients with chronic pain.

**Method:** Initial approach with evidence that supports chronic pain treatment and patient centered medicine, followed by a SWOT analysis to identify and plan future approaches of this challenging reality in clinical practice.

In the next phase, person-centered medicine principles and communication skills key points will be addressed

## Abuse of Procedural Right as a Doctors' Rights Protection Measure in the Light of Recent Changes in The Polish Legal System

Hanna Matyja

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Right to a (fair) trial is one of the most important human and citizens' rights. It is guaranteed by both constitutions of democratic states and international law acts, such as European Convention on Human Rights or Charter of the Fundamental Rights of the European Union.

Hence, a patient claiming damages against a doctor is exercising their fundamental right. Nevertheless, if we consider the number and diversity of actions being brought these days, the following question may appear: is it always the proper way to protect every demandant, regardless of other circumstances, especially their intention, a manner of execution of the right and finally- the outcomes seen from a doctor's perspective? The dilemma seems to be even bigger if we attend to the activity of some legal firms, like claims management companies and the phenomenon of so-called ambulance chasing, which are present in many countries.

The recent amendment to Polish Code of Civil Procedure established a new institution in our legal system which is abuse of procedural right. There is no knowing how the legal practice will look like; there is also a big controversy surrounding the issue. However, I believe it may be of great significance within legal relationships regarding medical law, especially for the protection of doctors' rights.



## How to Teach the First Syllabus

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Teaching the First Syllabus, second edition, at the High School is a relevant challenge.

The first question we have to ask is: why to teach it? Here are some possible answers: the First Syllabus is an effective tool that lets us regain dialogue as a means of processing thought and as a technique suitable for developing relationships. Dialogue makes use of maieutics, through a calm and balanced confrontation and through the formulation of dilemmas.

A second crucial question is: what is our purpose in teaching the First Syllabus? I would like to highlight some issues: my first goal is to enhance students' critical potential in social context, in order to promote their participation in the projects related to Citizenship Education. My second aim is to make students become informed and aware citizens, capable of making choices and taking their responsibilities.

I will provide two examples about how to use Syllabus Units in an interdisciplinary perspective at school.

## Paternalism in End-of-life Decisions in an African Setting: Any Cause to Worry?

Ijeoma Angela Meka  
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End-of-life and death are usually traumatic experiences for individuals and families. Among Igbo speaking tribe of South-Eastern Nigeria, once end-of-life becomes foreseeable, decisions are no longer left solely with the immediate family.

**Decision of end-of-life care:** The communitarian nature of African society considers it necessary to take the heavy decision of end-of-life care away from immediate family members. The usual decisions here involve continued hospital care or dying at home.

**Consent for burial:** In the western culture, while consent for burial is expected to rest with the immediate family of deceased, in eastern Nigeria, consent for burial for an adult lies with extended family members and community elders.

**Duration of mourning period:** This is solely determined by the community and/or religious institutions. This is to ensure proper burial rites to permit a smooth transition to eternity.

**Conclusion:** In Africa, communitarianism is mainly upheld at the end-of-life decisions as opposed to autonomy. This is targeted at protecting the immediate family of the deceased from unsound decisions taken out of grief, and also protect the interest of the deceased to ensure a smooth passage to eternity.

## Clinical Ethics Concerns and Access to Clinical Ethics Services in Rural Minnesota

Catherine McCarty, Keegan McCabe, Ray Christensen  
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Healthcare providers in rural areas encounter unique issues compared to their non-rural counterparts and a lack of specialty resources, including ethics services, can pose challenges to the delivery of optimal patient care. The purpose of this project was to identify ethical concerns faced by rural providers. Two-hundred-fifty-six rural physicians who serve as preceptors to medical students in rural Minnesota were contacted by email with a request to participate in an electronic survey. The survey included questions regarding access to clinical ethics services, recent ethical dilemmas encountered, and interest in a potential tele-ethics service. Twenty-nine percent of physicians responded, they had been in practice a median of 13.5 years. Fifty-nine percent have access to an ethics committee; 43% have 24/7 access. Ethical dilemmas were categorized into thirteen themes, with end-of-life care and vulnerable adult concerns most commonly identified. Online group-learning was the preferred training method for ethics education. Thirty-eight percent of providers indicated that they would likely use a tele-ethics service. In conclusion, providers in rural health systems face unique and complex ethical dilemmas and would likely utilize remote support for complex bioethical situations. The next step is to pilot a remote ethics consult service, to include policy development, education, and ethics case consultation.

## Ethical Challenge to Ethics Committee: A Qualitative Study

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In Italy the Ethics committees (EC) are the only institutional arena where to debate clinical ethical dilemmas. EC are also supposed to give advice and to counsel the hospital professionals on ethical issues. Though, the reference to EC for clinical ethical consultation is extremely low.

**Aim:** This study aimed to obtain nurses and physicians views on barriers of accessing and electing EC to support analysis and resolution of clinical ethical dilemmas.

**Methods:** Qualitative methods were used to investigate participant views and experiences. 9 nurses and 5 physicians working in a big hospital of Southern Italy were purposely selected to participate in semi-structured interviews. Data saturation was achieved.

**Results:** Four primary themes were identified: sense of lack of balance between EC members and clinicians, fear of being criticized, mistrust about being listened and involved in the debate, mistrust about transparency in discussion and decision making.

**Conclusions:** In the health professionals there is a lack of confidence in retaining that EC(s) could well support them in addressing and responding to clinical ethical dilemmas. EC(s) need to (re)build a network for trust and collaboration.

### Quali-Quantitative analysis of Empathy Levels in Medicine Students of a Brazilian Public University: First Step of a Longitudinal Research

Rodrigo Melo, Lucas Monteiro, Beatriz Braga, Angela Mendonça  
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Empathy can be summarized as the ability to place oneself in another's position. It is important in medical field and responsible for good doctor-patient relationship. Through its significance, this study aims to analyze empathy levels in first year medical students at Universidade Federal de Alagoas, in analogy to the American article that created the Jefferson Scale of Physician Empathy (JSPE). This research's objective is to evaluate empathy levels in those students and compare results to related literature. Application of the JSPE's Brazilian version through "Google Forms" and Focal Group usage were the basis of this quali-quantitative study. Then, both results were interpreted, using "Microsoft Office Excel 365" and "Iramuteq". Article research was made using "Scielo" and "Pubmed" databases with descriptors "Empatia", "Estudantes de medicina", "Medicina" and the Boolean operation "and" of those terms. JSPE's Medium Score was 86,6 ( $\pm$  33,0). For Focal Groups, Iramuteq's "Word cloud" and "Similitude analysis" tools had "gente", "médico" and "empatia" as the more frequently spoken terms by both genders. Student's empathy levels start low, contrasting to present literature. However, more research is needed before a final verdict is made, since this study's core is longitudinal.

### Have There Been Advances in Diagnosing Death 50 Years after the Harvard Brain Death Report?

George Mendz, Francis O'Keeffe  
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The 50-year legacy of the Harvard Committee Report that sought to define death according to whole-brain function criteria continues to generate a diversity of opinions regarding how death should be defined. Various perspectives show that doubts linger regarding (1) when brain death should be diagnosed, (2) the criteria to pinpoint the occurrence of death, and (3) the alignment of medical practice seeking to establish human death with these criteria. This study reviews and assesses several perspectives that have made significant contributions to the debate. Attention is given to alternative definitions of death that show how several views on diagnosing death depart from the recommendations of the Harvard Report. Appraisals of various arguments lead to the conclusion that changes in the definition of death have resulted from advances in the knowledge of human biology and in diagnostic medical techniques. Since criteria and indicative tests are required to establish the death of individuals, at any given time interim rules based on the best available evidence need to be applied to declare death, whilst at the same time they should remain open to modification.

### Services and Cost of Medical Assistance

Sérgio Melo  
*SERVAN, Brazil*

**Introduction:** The bioethics imposes limits, but it also shows paths. The cost of medical assistance makes us plan better service in basic care to avoid the high costs in preventions and treatments of diseases in secondary and tertiary attentions.

**Objective:** Expand knowledge about chosen themes, for better understanding of prevention and therapeutics forms. With the thought of improving medical assistance and to reduce the costs of the services provided.

**Method:** The data was analysed qualitatively, being presented, the main aspects found on thematic in discussion. Then, through the selection of publications of last 50 years, medical assistance services and costs were discussed.

**Discussion:** With new drugs and equipment for diagnosis and therapeutics, expand the chances of success in diseases prevention and treatment. In the basic attention, have the opportunity to prevent and treat diseases, avoid its evolution. With the worsening of pathology, move towards the need of approaches more complex. Then, increases costs of medical assistance.

**Final considerations:** The improve of life quality occurred with the improvement of services in primary attention.

### Data Economy in the Health Care Sector

Attila Menyhárd  
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Technological development, in particular expansion of informational technology in health care sector results in specific challenges with legal and ethical impacts and consequences which are difficult to estimate today. It is still not clear for us, how far the problems today are old phenomena in new clothes or require innovative, perhaps revolutionary changes in the law. Liability for intermediaries, agents and subcontractors (e.g. software developers), ownership of data (e.g. in internet of things), transfer of data (e.g. with mergers and acquisition of private hospitals) certainly require innovative solutions. Collecting health related personal data and developing algorithms to analyze them certainly are invaluable contribution for developing diagnostics and analyzing risks. Such data, however, may be, and actually are used to earn profit primarily with developing and selling products (drugs, instruments etc.) and services on the market. This raises not only new aspects of duty of disclosure in the legal relationship of the patient and the health care service provider but also issues of sharing the profit with the client as well. Allocation of property rights over data may provide answers for such questions. Such answers require new approach in our legal thinking.

## "Wandering in Dementia" Autonomy Vs. Safety

Doron Merims

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For the healthy population, walking is a common and favorable leisure-time activity. An equivalent activity for patients with dementia is "Wandering" (aimless walking). This common symptom affects up to 50% of patients, who may wonder for hours during the day. Wandering is considered to be a risk factor for elopement from home. In a protected dementia special care unit, safety concerns shift from elopement to the risk of falls, harmful interactions with other residents due to wandering into their "personal space", and higher chances of exposure to environmental hazards (e.g., a wet floor). Preventing wandering using the safety argument restrict patients from fulfilling their basic needs and limits their autonomy. In a study we conducted in dementia special-care units, wandering was found to be correlated with lower cognitive function. To our opinion, this finding indicates that although suffering from worse mental condition, wanderers have preserved motor competence which might be due to their constant walking. It is possible that wandering maintains physical fitness and postpones motor disability. In our study wandering was not found to be a risk factor for falls. Better understanding the risks and benefits of wandering in dementia, may help to develop strategies to enable patients' autonomy to wander around safely and to improve their quality of life.

## Tackling Cultural Pluralism in Responsible Prediction

Mayli Mertens

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Anoxic brain damage after cardiac arrest is one of the most common causes of coma worldwide. Unfortunately, during critical care, only two indicators for poor prognosis exist. Namely, the absence of either brain stem reflexes or bilateral cortical (N20) responses. Recent studies have shown, however, that continuous electroencephalographic (cEEG) monitoring during the first 72 hours after reanimation could provide a robust contributor to prediction of both good and poor outcome in postanoxic coma. This innovation in prognosis allows for early withdrawal of life-sustaining care (as soon as 12 hours after reanimation) in countries where the value of 'sanctity of life' at all costs is trumped by 'quality of life' arguments. However, for the innovative prognostic practice to be responsible in different settings across the globe, contextual differences such as religious and cultural background, the availability of technology and other resources, and variations in local clinical tradition must be considered. For the presentation, I will focus on the challenges and opportunities that cultural pluralism elicits. I'll argue that multi-contextual, empirical research is needed in order to generate a global conception of responsible innovation in medical care.

## Assessing the Clinical Ethical Competence of Postgraduate Medical Students

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**Background:** There has been rising public consciousness regarding the ethical conduct of medical practitioners, and complaints against physicians appear to be escalating. After completing their studies, healthcare professionals are expected to know ethical principles and apply them in their clinical practice. Hence, this study was conducted to assess clinical ethical competence of postgraduate medical students.

**Objective:** Assessment of the clinical ethical competence among postgraduate medical students of a medical college.

**Materials & Methods:** Cross sectional study was conducted among post graduate Medical students in a Government medical college. After obtaining permission from Institutional ethics committee, the purpose of the study and nature of information which has to be furnished from the students was explained to them. Data was collected among 135 medical postgraduate students using pre tested self-administered questionnaire.

**Results:** 103 (76%) have the ability to identify the moral aspects of medical practice. Very less awareness was found in ethical aspects of genetics i.e. 55 (41%) and ethical aspects of transplantation/organ donation (43%). 20 % study subjects were not having any information about ethics.

**Conclusions:** The fact that many respondents had neutral opinion to some questions may indicate their lack of awareness or knowledge in that area and their inability to decide. Hence there should be sufficient training classes, workshops, conferences to stress.

## Applied Ethics on Biomedical Engineering: Results of an Italian Project

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Biomedical Engineering (BE) is one fastest-growing engineering branches, especially since the 4.0 Industrial revolution. Due to it spread out have a clinical, cost-effectiveness, ethical and social impacts. This entail crucial improving the ethical background in bioengineering providers. Therefore, the ethical responsibilities of biomedical engineers include also a responsibility to respect general ethical principles and standards established by medical ethics and bioethics. In the light of this concept, since 2004 to present we have designed an experimental training project, called Troubleshooting Laboratory (TL) with the aim of improving the ethical approach to the career of the first year students of the Biomedical Engineering Master Degree, between synergy of the different fields as clinical, engineering and ethical. TL project is direct to give students, during 48 hours of stage, from one side a concrete experience in 20 Departments of the University Hospital of UCBM, from the other side to improving biomedical engineering level of responsibility, ability to problem solving into the Hospital and to improving Quality of Life. In particular, students will have the duty to find a concrete solution to problems existing into Hospital Departments. The contribution wants to show the positive results of this Ethics education on bioengineering students.

## Promoting Research Ethics through Peer Education: An Experience from IFMSA

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The International Federation of Medical Students' Associations (IFMSA) has been a strong advocate for Research Education since 1991. We believe that Responsible Research and Research Ethics should be at the core of Research Education for medical students. Therefore, IFMSA has developed 2 peer-led research ethics workshops that aim to teach basic concepts in Research Ethics to medical students.

The workshops were conducted by medical students in smaller groups of up to 20 participants at different IFMSA meetings - "Research Ethics" was conducted 2 times at peer-led Research Camps for a total of 40 participants and "Ethics in Exchanges" at least 6 times a year since 2013 at General Assemblies and other international events hosted by IFMSA. Both workshops focused on basic concepts such as Autonomy, Non-maleficence, Beneficence, Justice and Consent.

Several different engaging facilitation methods were used ranging from brainstorming, case discussions, debates as well as role playing, simulations and group review at the end of the training.

We present an example of a successful approach to peer-education on Ethics within Research. We believe that Research Education with an emphasis on ethics as a core principle of Research should be included in the medical curriculum as a mandatory topic.

## Kinship Impact on Understanding of Biobank-based Research: Donors Perspective in Latvia

Ilze Mileiko, Signe Mežinska, Jekaterina Kalēja

*Institute of Clinical and Preventive Medicine, University of Latvia, Latvia*

Our presentation aims to understand how the relationships with relatives influence decision-making about participation in research biobanks in Latvia.

**Methods:** 20 qualitative semi-structured interviews with donors of two biobanks in Latvia. Interviews were carried out in project "Ethically and socially responsible governance of research biobanks in Latvia: analysis of opinions of public, donors and researchers" (funded by the Latvian Council of Science, project No. LZP-2018/20171).

**Results:** Donation of biological samples to the research biobank usually is perceived as an individual decision of an autonomous person; however, our interviews showed that an individual's relationship with relatives can affect the willingness to donate samples.

Kinship was an important aspect when donors reflected about research ethics, informed consent, privacy and receiving results of the study. For example - donors were not sure how much information (health and lifestyle data) they can provide to the biobank about their family. It shows that information about relatives could become an important ethical issue.

Secondly, the interviews showed ethical challenges related to the incidental findings. Some donors believed that information on incidental findings can be important not only for the donor him/herself, but also for relatives. This leads to new discussions regarding rights to know and not to know. It is important to include issues related to kinship in the debate on research ethics.

## Whistleblowing in Healthcare Sector in Bosnia and Herzegovina: Legal and Ethical Issues

Igor Milinkovic

*University of Banja Luka, Bosnia and Herzegovina*

Corruption is a serious problem of global society which occurs in all countries. It also appears in almost all parts of the society. Corruption is particularly dangerous in the healthcare sector, since it can jeopardize patients' access to healthcare and reduce the quality of medical services. Among the means of combating corruption, a special importance is attributed to whistleblowing. In order to establish an effective whistleblowing system, it is necessary to provide an adequate legal protection to the persons who report corruption.

In the paper, the legal framework of the whistleblowers protection in Bosnia and Herzegovina will be explored. The laws on whistleblowers protection adopted at different government levels will be analyzed and compared with legal solutions accepted in other countries. A special attention will be given to the fight against corruption in the healthcare sector (and to the adequacy of adopted legal solutions for the protection of healthcare whistleblowers). The ethical dimension of whistleblowing will be analyzed as well, based on the analysis of the "standard" understanding of the ethical justification of whistleblowing, developed by Richard de George (De George, 1986), as well as the criticisms of this conception found in literature, including the understanding proposed by Hoffman and McNulty (Hoffman, McNulty, 2010).

## Holocaust Doctors: The Shadows of the Past Intertwined with the Present

Susan Miller

*Houston Methodist Hospital Research Institute, USA*

Some of the most difficult moral lessons to teach are those we have never learned or those we have un-learned from the past. The unanticipated, organized role of physicians and their subsequent radicalization under National Socialism resulted in both medical and research misconduct. This legacy continues to reverberate even though it has been more than seventy years since the Doctor's Trial was held in the occupation zone of Nuremberg, Germany (United States of America v. Karl Brandt, et al.). Specifically, these defendants were charged with, among other things, the performance of medical experiments on civilians and prisoners of war without the subjects' consent. This unethical research and the associated medical genocide occurred in hospitals, nursing homes, "asylums" and concentration camps. Physicians inexplicably played an essential role in furthering Nazi policy and were an instrument for Hitler's totalitarian control. Furthermore, the medicalization of Rassenhygiene was an essential pre-condition for the Holocaust as racial purification was considered a step to "heal" society through "killing."

Unfortunately, dysfunctional psychological attitudes, including cognitive dissonance and dehumanization, continue to persist. This presentation will explore the implications of ideological and psychological corruption of medical and research systems by using Germany history as a case study to illustrate an educational mechanism of preventive ethics.



## Spiritual Care Program Embedded Within a Tertiary Care Hospital

Charles Millikan  
Houston Methodist Hospital, USA

Houston Methodist, a large tertiary hospital in Houston, Texas, provided services to 118,000 inpatients in 2019. At the center of its patient care are the I CARE values of Integrity, Compassion, Accountability, Respect, and Excellence coupled with a mission commitment of serving all "in a spiritual environment of caring." The hospital's core advocacy, is based on a strong spiritual-care focus, incorporating 82 Chaplains, 292 Chaplaincy Care Volunteers, and a system-wide Clinical Pastoral Education Program. In addition to this spiritual-care component, Houston Methodist also has a robust commitment to bioethics through its relationships with Baylor College of Medicine, with 500 annual consults, alongside a Fellowship Program in Consultation Ethics with Weill Cornell and New York Presbyterian Hospital. Chaplains have regular clinical assignments with daily debriefings. Philanthropy supplements patient care expenses and has created a separate, model chaplaincy program dedicated exclusively to physicians and staff. The Spiritual Care service also has a relationship with the hospital's Community Benefits Program and assists patients in securing a medical home through its network-of-care programs with several federally-qualified and faith-based clinics in the greater Houston area. In addition, diverse faith-based congregations further serve these patients in helping to mitigate the social determinants that prohibit healthy living.

## Is Virtue Theory Any Use in Medical Ethics?

David Misselbrook  
Royal College of Surgeons in Ireland Bahrain, Bahrain

The relationship between medical ethics and moral theory is often problematic. The role of culture in both moral theory and ethics adds a further complication. For such reasons "checklist" approaches to ethics, such as Principlism or the Four Questions Method, are often seen as more acceptable as they do not depend on any specific commitment to moral theory.

In contrast, the moral system of Virtue Theory has experienced a resurgence over recent decades. But Virtue Theory is often accused of not being adequately action directing, a key requirement for successful ethical theories. Furthermore, in its essential form it does not sit easily with insights from duty based or utilitarian moral theories.

This presentation examines the case for a greater use of Virtue Theory as a source of both medical ethics and professionalism in healthcare. The presentation offers a reinterpretation of Aristotelian virtues within a 21st century context. It also clarifies the second poorly understood axis of virtue theory – that of the social context of an action.

The presentation proposes two "controlling virtues" for healthcare – the virtues of compassion and phronesis (or practical wisdom).

## The Helsinki Committee Challenges During COVID-19 Pandemic

Malka Mishel<sup>1</sup>, Keren Amar<sup>1</sup>, Amos Katz<sup>2</sup>  
<sup>1</sup>Barzilai Medical Center, Israel  
<sup>2</sup>Edith Wolfson Medical Center, Israel

The COVID-19 pandemic brought changes in many fields, including the clinical trials, and the regulation regarding them. The Israeli MOH regulation adjusted frequently, and accordingly the Helsinki Committee work which was required to adapt itself. We compared our work between March 2020 to November 2021, to previous years. Immediately within the first closure we moved to remote meetings. To adjust the new protocols influx that addressed the pressing public health emergency, we added to our 12 annual pre-arranged monthly meetings, 18 urgent ones. A total of 40 meetings in 21 months, 50% increase. The enormous effort and commitment shown by Helsinki committee members and research administrators was without any staff changes. Urgent meetings were scheduled within days from the submission. We reviewed 207 studies, a growth of 27% compared to previous 2 years. 22% of the studies, were on COVID-19, evaluating drugs, medical devices, procedures, and retrospectives analysis. Some of the COVID-19 studies that were approved by the Helsinki Committee, weren't done due to the frequent changes in leading treatment trends and patients' condition. We hope to maintain the online efficacy work, also after the pandemic and generate sustainable improvements of the committee processes, like working paperless and totally digital.

## Hearing the Unheard: Testimonial Injustice in Clinical Pain Management

Claire Moore  
Yale University, USA

Testimonial injustice occurs when a person's word is considered less credible due to prejudice. Some scholars argue that illness causes patients to be vulnerable to testimonial injustice due to perceptions of compromised cognition and heightened distress. Despite this initial research, the intersection of illness and patient identity in further altering epistemic credibility in the U.S. has not been examined. This poster examines how patient race and gender exacerbate deficits in credibility which lead to disparities in pain care. Specifically, this poster reveals how race can degrade the credibility of patients of color suffering from chronic pain as well as how gendered normalizations of postpartum pain silence women about maternal complications. Analyses of testimonial injustice in medicine illustrate how fundamental features of medical practice, rather than mere bias, enable systemic ignorance to patient perspectives. These features include methods of pain assessment such as numeric scale-rating that ignore embodied experiences of pain and paternalistic perceptions of patients as agents fundamentally lacking in clinically relevant information. Thus, this poster will ultimately advocate for the potentials of narrative medicine in reframing the patient as a source of valuable knowledge and the physician as a listener within a joint information-sharing process.



## Nothing about us without us: A Disability Challenge to Bioethics

Sagit Mor  
University of Haifa, Israel

Disability theory and disability activism pose a fundamental challenge to bioethics. Bioethics has historically endorsed an individual-medical approach to disability, which prioritizes medical-professional knowledge over disabled people's experiential knowledge. The disability challenge to bioethics involves a new understanding of disability and a new place for disabled people as active participants in decisions making processes, as manifested in the disability rights movement's slogan: Nothing about us without us. My talk will introduce a reading of this slogan as a call for individual and collective voice and representation in decision-making processes. The individual dimension concerns personal decisions regarding one's own life. The collective dimension concerns the involvement of disabled people as a group, in all levels of public deliberation, including policymaking, legislative processes, or public committees. The talk will also call to institutionalize the incorporation of disabled people voices and perspectives into public deliberation processes. The latter is illustrated through the involvement of the Israeli Disability Rights Commission in the legal developments concerning wrongful life claims in Israel. Finally, I will claim that the disability challenge to bioethics has far reaching consequences for any legal and political context in which medical knowledge is utilized and prioritized.

## What should the Good Life for Dysphagic Elderly Patients be under Palliative Care?

Marcio Moreira, Luciana Garbayo  
University of Central Florida, USA

Many dysphagic elderly patients under palliative care in the Intensive Care Unit (ICU) have previous swallowing difficulties that get worse with the hospitalization process and with frequent intubation procedures. While affecting their wellbeing – inclusive of their pleasure of eating, their personal, social and cultural preferences and identity in the delicate end-of-life period - these swallowing difficulties also impact directly the patients' experience of care regarding the valuation of their autonomy. Despite its importance, this care dimension is less visible as an opportunity of ethical, autonomous, patient-centered decision-making in traditional ICU care. Yet, it is a crucial area of ethical shared decision-making for the speech pathologist in the ICU. Other point to reflect on is the process of patient's assertive communication as well as the maintenance of the autonomy for expressing their beliefs and desires in the context of ICU. This study discusses the meaning of the good life for dysphagic elderly patients in the ICU, in a patient-centered, shared decision-making value-theoretic platform. We present the hedonist view and the meaningfulness of food for dysphagic elderly patients be under palliative care.

## GPs' Views and Experiences on Population-Based Preconception Expanded Carrier Screening in the Netherlands: An Empirical Bioethical Study

Sofia Morberg Jämterud<sup>1</sup>, Anke Snoek<sup>2</sup>, Irene van Langen<sup>3</sup>, Marian Verkerk<sup>3</sup>, Kristin Zeiler<sup>1</sup>

<sup>1</sup>Linköping University, Sweden

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<sup>3</sup>University of Groningen, Netherlands

**Background:** Between 2016 and 2017, population-based preconception expanded carrier screening (ECS) was offered to 4,295 couples in the Netherlands during a pilot study. From 2018, it was possible for all couples in the Netherlands to ask to have such an ECS test from six specially trained general practitioners. Little is known about the GPs' views on and experiences of preconception ECS.

**Aim:** The aim of this study was to offer an empirical bioethics analysis of preconception expanded carrier screening, from the perspectives of GPs.

**Methods:** Empirical bioethics: thematic analysis of semi-structured interviews combined with ethical discussion.

**Results:** Two themes were identified. The first theme, 'choice and its complexity', highlighted the need for shared relational autonomous decision-making within the couple. The second theme, 'preconception ECS as prompting existential concerns', highlighted how perceptions and understandings of preconception ECS are shaped by values and norms of what it means to be human and live together with others in a specific socio-cultural context.

**Conclusion:** The study presents two recommendations: 1) Careful training in genetic counselling to GPs who are to offer preconception ECS, targeting shared relational decision-making within the couple. 2) More attention should be given to existential genetics, i.e. to existential issues evoked by genetics.

## Digital Pills: Patient Autonomy Challenged in the New Era of Digital Medicine

Marina Morla González  
University of León, Spain

The recent approval by the Food and Drug Administration (USA) of the very first digital pill has triggered multiple reactions among scientific circles. We are referring to the first medicine which incorporates a digital sensor that tracks ingestion and thus measures the patient's adherence to the treatment. When the pill (and the sensor inside it) is ingested, it automatically sends a signal to a patch worn by the patient, indicating what medication has been taken, at what time and at what dose. In addition, the patch collects other kinds of health data: heart rate, rest time, steps taken, etc. And all that information is encrypted and sent via Bluetooth to the app in the patient's smartphone, to that of their relatives and to their doctor in their health portal. The usefulness of this last development in digital medicine is undeniable, although the risks implied for the patient are not trivial. From an ethical and legal point of view, we will focus, firstly, on how patient's autonomy is challenged from multiple perspectives, such as the scope of patient's informed consent in relation to the developer's app privacy policy, etc.; and, secondly, on the main incentives for developing this last pharmaceutical product.

## Formal Bioethics Instruction in Saudi Medical Schools: Challenges and Solutions

Ruaim Muaygil  
King Saud University, Saudi Arabia

In Saudi Arabia, bioethics is a field in its infancy. As Saudi medical schools look to incorporate formal bioethics instruction into their curricula, several obstacles are identified. First, bioethics remains an elusive discipline to healthcare practitioners, a direct result of traditionally cursory bioethics education which left out central aspects of bioethics such as moral philosophy, critical thinking, and contextual engagement. Second, a suboptimal introduction to bioethics has resulted in a significant shortage of qualified and formally trained bioethicists. Indeed, a majority of Saudi bioethicists are self-taught physicians who balance their bioethics work with their clinical duties. Third, absent a vibrant community, bioethics scholarship is noticeably, and understandably, limited. Much of what does exist follows conventional scientific writing methods and lacks the theoretical dialogue and critical analysis essential to bioethics scholarship.

This paper aims to discuss these specific challenges further, and to provide practical solutions for the creation, promotion, and evaluation of formal bioethics instruction in Saudi Arabia. It puts forth both immediate and long-term suggestions for the establishment and maintenance of a rigorous curriculum at the undergraduate level, in the aims of producing a lively, locally informed, and culturally relevant bioethics discipline that enhances the Saudi healthcare system.

## Bioethics 2020: Perfect Vision or Time to Re-focus?

Michelle Mullen  
University of Ottawa/CHEO Ottawa, Canada

Bioethics has emerged as a global and enduring feature of medical and healthcare education, clinical and hospital service, the academy, and popular culture. With these successes, however, are equally enduring challenges of agreed upon discourse and method to inform our deliberations. We are witnessing the rise of various faith-based bioethics and emergent geopolitical bioethics lenses. These alternatives are generally framed as bioethics construed in distinction to "Western" bioethics: 'principlism' and 'practical ethics' in particular. Examples include African, Asian and Indigenous bioethics discourse. In clinical settings, bioethics teachers find that they may be teaching within two domains: what is required for the examination and what might be helpful with a bioethics problem involving real humans and in real time. How ought we to address the seemingly growing disconnect between bioethics as it is entrenched in textbooks and policy documents, and the needs of diverse persons and communities in the context of bioethics from bedside to the legislature? This paper examines these concerns via 'practiced' (not 'practical') bioethics in diverse post-colonial settings. The process of muddling through with emphasis on diversity and human rights in the service of actual persons is described and its implications for re-imagining bioethics as dynamic.

## Biomedical Research Involving Youth: Interrogating the Boundaries of Autonomy and Vulnerability

Maria Cristina Murano  
Italy

Given the tragic legacy of unscrupulous research conducted on human subjects during the 20th century, ethics debates and regulations have taken a precautionary approach that gives pivotal attention to individual autonomy and protection of vulnerable subjects. While this approach has led to a much-needed increase of awareness about the importance of respecting human dignity and human rights in biomedical research and clinical trials, previous studies have express concern that it might lead to two unintended consequences: 1) it might overshadow positive understandings of clinical trials; 2) it might limit participation of adolescents and young adults. This presentation explores a more philosophical unintended consequence: the framing of current international regulations on biomedical research might unwittingly suggest a clear-cut distinction between "the autonomous adult" and "the vulnerable minor". As philosophical concepts, vulnerability and autonomy are complex and nuanced, and may also coexist. This presentation provides a situated and existential account of youth experiences and stresses the need to acknowledge both youth's demand for autonomy and their condition of vulnerability.

## Return of Individual Genomic Results: Perspectives of Genomic Researchers in Uganda

Erisa Mwaka, Deborah Ekusia, David Mafigiri, Ian Munabi  
Makerere University, Uganda

**Introduction:** In Uganda, most genetic studies have no provision or framework for returning results of their genomic analyses to research participants.

**Objectives:** The study aimed to explore the experiences and perspectives of genomic researchers on the return of individual results in genomic research.

**Methods:** We adopted a qualitative research approach that employed 16 in-depth interviews with researchers involved in genomic research. A contextualized thematic approach was used to interpret the results supported by representative quotes.

**Results:** Six themes emerged from the data including the limited knowledge of researchers and research ethics committees (REC) on the ethical and societal implications of returning genomics results; perceived risks; perceived benefits; the need for community engagement through community outreach programs and community interventions; researchers' opinions on the return of individual results including actionable incidental findings and the modes of delivery of results; challenges to return of results; and recommendation for safe return of results. Researchers opined that there was lack of local capacity to analyze and interpret genomic data and there are logistical challenges in returning results.

**Conclusion:** There is need for community engagement and the training of local researchers and RECs on genomics and the implications of return of results.

## **Biotechnological Risks Phenomena: From Risk Analysis to Risk Governance as a Route Towards Bioethical Maturation**

Konstantina Mylona-Giannakakou  
*National & Kapodistrian University of Athens (NKUA), Greece*

A rather common agreement is that a successful future of bioethics lies in the ways that it copes with the inherent risk characteristic of biotechnologies that pertains to both methods and products. Typical biotechnological risks posed new challenges in risk analysis and eventually moved the focus to risk governance. Currently there is considerable debate as to whether this focus shift from the technical and analytical tools signifies a deeper structural change in our bioethical model or is a simple linguistic adjustment. In this analysis I advocate firstly that risk analysis assists in the assessment of the phenomena but is incomplete by itself to recommend the type of systematicity and principles we need for an altered future where a dialogue across discipline boundaries is more advantageous. Secondly, risk governance is not a definitional translation of hitherto unsuccessful traditional ways to address novel types of risks. The risk-based re-definition of life obliges us to adopt and adapt to a socioethical understanding of continuing transition risks across societies. Thus, risk governance by becoming a lens through which a specific bioethical future has been envisioned represents the next level in our bioethical maturation process.

## **CRISPR and Patents: A South African Perspective on the CRISPR Patent Landscape**

Meshandren Naidoo  
*University of KwaZulu Natal, South Africa*

CRISPR raises two novel questions in South African (SA) intellectual property law: 1) Whether, on a technical legal level, altered human genetic material is patentable; and 2) whether, on an ethical level, said material is patentable.

Global ethics discourse in the patent landscape is routed in Western ideals, with scarce consideration of African values and notions. I present an Africanized view that will be introduced through the lens of the morality clause – an ethical tool operating as a legal bar to patent eligibility of certain inventions. I also consider neglected Constitutionally enshrined rights – such as privacy and freedom and security of person. In answering both questions, I argue that SA law does allow for the patenting of genetic material and should allow for it. Rather than restricting the patenting of altered genetic materials which would reduce the dissemination of innovative and valuable knowledge, a controlled patent license could be used as a tool that is suitable, unlike the broad morality clause, to create an outcome in the human therapeutics industry that is sensitive to a South African public health context, whilst still fostering innovation.

## **The Ethical Object Revisited: A New Ethical Object Approach to Ethical Analysis**

Ramon Nadres  
*Catholic University of Widya Mandala Surabaya, Indonesia*

The Moral Object of an action has traditionally been the centerpiece of ethical analysis. As years passed, however, the use of the moral object as the touchstone of morality was probably weakened by what may have been perceived as its "dogmatic air". This paper proposes to revisit the moral object as a key element in ethical analysis, but this time opening it up to ethical stances other than the traditional one usually linked with it. To start with, it takes the new name "Ethical Object" instead of "moral object", to disengage it with previous theological undertones. The main thrust of the analysis is for the moral agent to ask the question: "what am I actually doing"; and to answer it with an honest and open heart. The method requires the review of all the possible answers to that question from all the varying and even contrasting sides of the issue. Once all the possible answers are in, they are reviewed so that one can sift out what can truly characterize the present moral act. The action is assessed from the micro-ethical, meso-ethical and macro-ethical points of view.

## **A Historical Overview of Prenatal Screening and Testing Technologies' Development: What Should We Learn from The Past to Face Perpetual Issues Related to Women's Choices about Prenatal Screening and Testing?**

Panagiota Nakou  
*University of Manchester, UK*

An enduring ethical dispute accompanies prenatal screening and testing (PDS) technologies in their longstanding presence in the clinical setting. Particularly, regarding the idea of reproductive choice, since their debut until today, on one side of the dispute are those who have supported PDS as a way to empower women's reproductive choice, while on the other side are those who have raised concerns about limited deliberate choice within the context of wide and routine PDS use. Empirical research confirms such concerns, providing evidence about recurrent problems related to women's autonomous decision-making when it comes to prenatal screening choices. Considering this perpetual tension between the opposing sides, in this work, I provide a historical overview of PDS technologies' development aiming to reveal the root causes of this tension. Essentially, I explore motivations which significantly contributed to the wide use of these technologies and I conclude that such a wide use was adopted to achieve a number of wholly different aims other than women's choice empowerment. Ultimately, I argue that those different aims and women's choice empowerment are irreconcilable; whereas the former fit in with a routine system, if we aim to safeguard the latter, we should redefine the context of PDS systems.

## Discovering my Aphasic Patient Will at the End of Life

Liz Nascimento  
University of Porto, Portugal

**Introduction:** Each person in the world has a different way to live and think as well as dying. If on the one hand for a non-aphasic one it is difficult to understand and express their own will, on the other hand for an aphasic patient it can be an enormous barrier.

Also, sometimes a stressful situation emerges in the relationship among patient, family, and health care team when they try to communicate in an unstructured way.

**Aim:** This paper aims to clarify how the multidisciplinary team, supported by a speech-language-pathologist (SLP), should be able to identify some of the desires of aphasic patients at the end of life.

**Method:** A literature review was conducted of two important databases.

**Results/Discussion:** The literature is centered on the aphasic decision-making capacity rather than discovering the mainly desire of all that people. There are few studies which contains association between SLP and the decision-making capacity. Also, no studies about aphasia and wishes at the end of life were found.

**Conclusion:** Therefore it becomes more challenging to offer a quality supportive and palliative care at the end of life when the real will of the sick person is unknown. It is a question to start being concerned about.

## The importance of incorporating Cultural Sensitivity in the Bioethics Education among Medical Schools: Lessons from the Asia-Pacific Region

Olivia Ngan, HK Ng  
The Chinese University of Hong Kong, Hong Kong

Contemporary bioethics education has been developed predominately within Euro-American contexts, and other regions across the globe are joining the field. Many standard bioethics materials retain a narrow geographic focus from the Western experiences and culture, raising concerns about applicability to other world regions that have a history and cultures with many unique features.

This presentation describes how learning receptivity among medical students differ when using Western-centered case study and regional-specific examples, as well as difficulties of building capacity in resource-limited settings. Examples are contributed by a group of interested medical teachers from the Asia Pacific Bioethics Education Network.

Our teaching experience suggests the essence of "3R" in the bioethics education, which are real – adopt existent cases over hypothetical scenario; relevant – connect bioethics topics with students' future career, and relatable – teach students to relate to the learning content. Passive learning attitude was observed when using Western-centered case only, whereas active participation was reported when local sociocultural values were considered in the case studies. Bioethics educators shall not neglect cultural sensitivity in the curriculum design and implementation to cultivate lasting bioethical awareness and lead a rich global understanding among students.

## The Christensen Project: Serving the Underserved Through Psychiatry

Caroline Nickerson  
University of Florida, USA

In an interview, a former patient described Dr. Richard C. Christensen as the embodiment of unconditional love. Tragically, his life was cut short in November 2015 when he was hit by a motor vehicle while out for a morning run. His legacy continues through numerous projects and community service initiatives organized by coalitions of family members and friends, as well as former students and colleagues from the University of Florida and the Sulzbacher Center. The Christensen Memorial Project, established by the UF Psychiatry Department, has launched a three-pronged effort in Dr. Christensen's honor to showcase, through his life and work, the importance of having compassion, serving the underserved through psychiatry, and ministering to people who are homeless. The project's components are (1) a compilation of nuggets of wisdom from Dr. Christensen in a textbook, teaching booklet called the "Christensen Pearls," (2) a model medical ethics curriculum, and (3) a ongoing teaching website. Though this presentation will showcase parts of the Christensen Pearls and the model medical ethics curriculum (which has been peer-reviewed and accepted by the American Association of Directors of Psychiatry Residency Training, known as AADPRT), the majority of this presentation will focus on the over ten interviews conducted by Caroline Nickerson of Dr. Christensen's family, friends, colleagues, and patients, presented in an oral history format and with relevance to bioethics education.

## Implementation of End-of-Life Legislation

Rachel Nissanholtz Gannot  
Ariel University, Israel

The development of life sustaining technologies has raised moral and ethical issues regarding quality End of Life [EOL] care. In Israel, the Dying Patient Law was enacted in 2005, asserting the right to avoid medical care in certain circumstances. However, this legislation has encountered implementation barriers, as has similar legislation in other countries.

Our goal was to examine what are the main barriers to implementing the law and to delivering better EOL care.

35 open in-depth interviews with professionals who deal with EOL patients or EOL policy at different institutions: MOH, the four health funds, hospitals, hospices and assisted-living facilities.

The Ministry of Health [MOH] and the health funds promote programs to help people at the end of their lives take charge of their life. However, there are barriers, such as: Parts of the law that are bureaucratic and incompatible with clinical reality; absence of standards for proper implementation and a lack of clarity regarding division of responsibility; and difficulties associated with initiating EOL discussions, such as emotional difficulties and insufficient training.

Legislation in this area raises awareness regarding EOL issues and drives responsible parties to take actions. However, there is more to be done; establishing clear standards for implementation, and investing resources in ongoing training for medical staff, are crucial to advancing the proper treatment for people at the end of their lives.



### **Does Anonymous Data Always Cause No Harm? A Case Concerning the Legality of Using a Female Patient's Identifiable Naked Photos for Advertisement**

Huei-Chih Niu  
*China Medical University, Taiwan*

A recent regulatory trend is to allow people to provide anonymous health data for Artificial Intelligence (AI) to "learn", so as to improve the accuracy of AI in healthcare. It is declared that anonymous data cause no harm to patients' privacy. A case in Taiwan however suggests emotional harm may not be removed simply because the connection between a patient and health data is cut off. A patient found her headless naked photos are posted by a clinic on its website for advertisement after she received a breast surgery. She felt depressed realizing her topless photos may be seen by anyone without her permission. Taiwan's Personal Data Protection Act (PDPA) clearly defines that only data that are possible to directly or indirectly identify a natural person is personal data. As a result, these photos are no longer her personal data; emotional harm caused by her unpleasant feeling and sense of shame is not subject to the protection of the PDPA. Given the fact that similar subjective and sensitive emotional damage of a victim is legally recognizable and protected in cases like sexual harassment, it is necessary to reconsider the appropriateness of the approach - anonymous data can cause no harm.

### **The State of Art of Frozen Embryos' s Succession in Brazil**

Maria Carolina Nomura-Santiago  
*Universidade São Judas Tadeu, Brazil*

Are cryopreserved embryos legal successors? In order to answer this question, first, it is important to define the status of frozen embryos: if they have personality or rights while they are still cryopreserved. In Brazil, there is no law regarding human artificial reproduction, however embryos that are already implanted have rights and are protected by law. Whereas the frozen embryo must be implanted to be protected. So, if a person dies and leaves frozen embryos behind, if there is no formal authorization in a will for the widow to implant those embryos, it will not be possible to carry on the parental project. That is a great problem, since the only rule in Brazil that deals with that issue was created by the Federal Medical Council, which is not a proper legislator. That rule allows post mortem reproduction, since the partner has left a consent. But the consent those people believe they have is the one they gave at the fertility clinics, not in a will. So, when they intend to seek the parental project after his/her partner's death, they are stopped by a judicial order that interprets that authorization as the one made throughout a will.

### **"Animals are not Machines" (Jean Meslier): A Modern Reflection on Animal Sensitivity**

Ricardo Noguera-Solano  
*Univesidad Nacional Autónoma de México, México*

In his "Testament: Memoir of the Thoughts and Sentiments of Jean Meslier" (1729), the author, a little-known French philosopher, developed a critique of Rene Descartes' proposition where he equated organisms with machines, lacking in sensitivity. Meslier found the idea of not accepting animal sensitivity disconcerting. From his perspective, it was easy to see that animal nature "resembles the sensitive nature of human beings", and that animals and human beings are merely different expressions of the organization of matter, with profoundly similar brain physiology. Convinced of the above, he argued that animals "think, feel and experience existence through their material organization", and in a similar way have "an animal humanity."

Taking the above into account, it is the objective of this text to show that Meslier's reflections may be considered the first materialist treatise in contemporary discussions defending animal sensitivity. His Testament is not only a book on philosophical materialism that contrasts with Cartesian mechanism and modern idealism, it is also a political agenda that, among other issues, proposes the construction of a "new type of relationship with animals" based on the recognition of their sensitivity and on the practice of Pity.

### **Strengthening Perceptions of Ethical Competence among Nursing Students and Graduates**

Samira Obeid, Michal Man  
*The Max Stern Yezreel Valley College, Israel*

Ethical competence is part of all healthcare professionals' general competence. Ethics education aims to increase nursing students' and nursing graduates' ethical self-confidence. Previous research has found many gaps in ethical education content and poor understanding of how these gaps affect graduates.

The current study aims to evaluate an advanced education workshop aimed at strengthening the self-perceptions of ethical competence of nursing students using the Generalized Self-Efficacy Scale and at three points in time: before the workshop, after the workshop, and after graduation.

Results: statistically significant differences were found in overall self-efficacy: before the workshop (mean of 2.42); after the workshop (mean of 2.13); and for graduates (mean of 1.58) with  $p0.000$  on a scale ranging from 1-5 (1 indicating high self-efficacy). Mean scores for students after the workshop and for graduates were 7.8 and 7.25, respectively, on a scale ranging from 1-10, where 10 indicates high self-efficacy. Graduates presented a high mean score regarding their ability to cope with ethical dilemmas when compared to other nurses working with them (mean of 7.4, on a scale ranging from 1-10). To conclude, levels of self-efficacy with regard to coping with ethical dilemmas increased over time, suggesting that the workshop strengthened the self-perception of ethical competence for nursing students and graduates.



## The Power of Stories: Do They Even Need to Be True? A Case Presentation

Stephen Offord  
Saratoga Hospital, USA

Stories are powerful. This is illustrated on the geopolitical (the story of ISIS for example), religious, and personal level. This is a case presentation of a 50-year-old gentleman with debilitating abdominal pain who has an extra-ordinary story. His story impacts his disease. Yet as his story becomes increasingly out of the ordinary, one can't help but ask, 'Is it even true?'. But perhaps, more importantly, does it need to be true? That is, if it's his story, and he believes in it, isn't that enough? To give one example, the story of Mormonism is often dismissed if not made the object of ridicule (see Broadway's, 'The Book of Mormon'). Yet no one denies that Mormon people are real, or that their belief in their story is real, or even that their belief in their story has made them all the better for it.<sup>1</sup> So how much does it matter whether or not the literal story of Mormonism is true? Similarly, it is not the dedication to their story, more than the story itself, that makes ISIS so powerful? This presentation uses an extra-ordinary personal story as a launching point for a wider discussion on the importance of truth.

## Coherence in Science Research Ethics & Policies

Andreia Oliveira, Rui Nunes, Ivone Duarte  
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The rightful conduct in biological sciences is a recent object of study. Emerging alongside with the revolution of human rights driven by the aftermath of the two World Wars, there was a spread of guidelines aiming to establish an integrated, straightforward and rights-based conduct of scientific research. The aim of this research is to explore how is science conducted, what issues are we lacking to address and what is the role of ethics.

We gathered relevant documents created aiming the regulation of integrated science research written in the last ten years. After a first reading, we separated the text components referring to the following categories: responsibility, conduct, authorship, open science and data sharing, study design, and goals of the study. A second reading was made comparing each document under the named categories, with aiming to identify the overlap of content present in the documents and identifying missing issues to be addressed.

Our analysis shows that there is a tendency for the same topics to be covered in guiding documents, however, progressively incomplete, possibly due to the increasing complexity that is building within a certain thematic, lacking to mention emergent topics, such as Artificial Intelligence.

## Bioethics Principles in iPSC Research: The need for a Code of Ethics?

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<sup>5</sup>Cardiff University, UK

Generation and use of patient induced pluripotent stem cells (iPSC) has huge potential for research practice, particularly in translational medicine. However, it raises questions of research ethics beyond that normally associated with use of patient samples.

This presentation reports the outcome of a short-term scientific meeting (STSM) supported by COST ACTION 16210 – Maximising Impact of Research in Neurodevelopmental Disorders (MINDDDS), to consider these issues for the study of rare neurodevelopmental disorders. Several ethical issues were identified with regard to the processes of collection, manipulation and, particularly, in the use of human-derived induced pluripotent cells (iPSC). In general, the use of iPSC for clinical purposes per se – cell treatment or drug discovery – may be considered beneficent and the attainment of more and better knowledge desirable; however even these apparently non-maleficent purposes may entail conflicts of interest, lack of transparency or unfairness.

The authors will propose a Code of Ethics for scientists and clinical researchers dealing with iPSC, which may also serve as a basis for future guidelines to be included in the COST Action 16210 Knowledge Nexus. The ultimate goal is to promote the highest standards of practice, responsibility and adequate behaviour among scientists working with iPSC.

## Telemedicine, Access to Health and Medical Autonomy: A Brazilian Case Report

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**Introduction:** The “e-Health Strategy for Brazil” is a program of the Brazilian Ministry of Health that aims to expand and improve the health services network, especially in Primary Health Care, and its interaction with other levels of assistance, meeting the basic principles of health care quality, reducing queues for access to medical specialties and avoiding unnecessary displacement of patients and health professionals; based mainly on teleconsultation between health professionals to clarify doubts regarding clinical procedures, health procedures and issues related to the work process.

**Case Report:** This is a case report of the use of the Digital Health program in a southern Brazilian state and its implications when included in the process of patients' regulation and referral to specialized services.

**Discussion:** In order to avoid the number of queues, state managers conditioned the referral of primary care cases to the acceptance of regulatory physicians, in detriment to the evaluation of the presential physician, ascending the debate about medical autonomy, access to health and ethical implications on the use of telemedicine.

**Conclusion:** The telemedicine has several bioethical nuances that must be analyzed and regulated in order to protect values such as patient safety, medical autonomy and doctor-patient relationship.

## Parents, Children and Donors in the Bioethical Networks of the Conception by Gamete Donation

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This document is part of the UBACYT Project: "The competences of psychologists in the field of assisted reproduction techniques" UBACYT 20020190100120BA.

Morality is constituted by a network of discourses and practices that constitute epochal subjectivities. A bioethical reflection does not take place in a downward path from great principles to practices but must go in the opposite direction.

I propose as a hypothesis of this work to start from the discursive frameworks, practices, customs, which occur empirically in the realities of reproduction centers, in social networks, in what has been said and not said about the conception of children born by donating gametes and from there reflecting on the principles on which these practices are sustained. In this tour, we will see the distance between the practices and their bioethical foundations.

## Health Data Ownership: Establishing the Patient as the Owner

Kamilla Østerberg  
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Collections of health data can transform patient care and medicine. Big (health) Data is foreseen to move us beyond mere treatment, and toward a predictive, preventive, personalized and participatory medicine, where citizens not just contribute data that monitor health at a citizen level but also optimize own health.

This 'democratization' of health care is a trending topic and a promising aspiration in a world of limited resources. But it needs data to fulfill its potential. And while health data exists in abundance, the understanding of who, when, and how people should access this sensitive information, is only getting more confusing. The current ownership model, where personal data are "owned" by hospitals and doctors, has received critique for being paternalistic. Yet, solid theoretical foundations that establish patients as data owners have been lacking.

In this article, I utilize an ownership theory established by Hegel, known as the personhood theory, in order to demonstrate that some personal data are closely bound up with our personhood. Thus, by articulating the ways data are part of our make-ups as moral and communal individuals, I make an argument for why we ought to recognize patient ownership in some personal health data.

## What's Up, (Robo)Doc? Uniting the Nations of Artificial Intelligence, Medical Law and Ethics

Rory O'Sullivan-Hennessy  
University of Dublin, Ireland

Healthcare stands at the cusp of an Artificial Intelligence (AI) revolution. Medical science and healthcare technologies are beginning to cross frontiers in robotics and machine learning. However, the happy marriage of emerging, potentially sentient technologies with age-old, traditional principles of medical ethics and established legal frameworks, has an uncertain (but by no means inauspicious) future.

While the use of AI technologies in medicine continues to promise unprecedented transformative potential for healthcare provision and delivery, it continues to raise significant ethical, social and legal concerns. Core issues at the heart of the AI bioethics debate include: the ways in which respect for patient autonomy can be assured in AI systems; the risks of automation bias in healthcare services; the potential for radical changes in the clinician/patient relationship; issues of medical safety and accountability for AI technologies; and the potential for the malicious use and manipulation of medical AI.

This presentation – a necessary discussion in the face of a head-on collision with the Fourth Industrial Revolution – will address these core issues and more. It is time to begin addressing the legal and bioethical landscape for these emerging technologies, for the benefit of international healthcare delivery – before it is, quite simply, too late.

## The Human Rights of People with ID and Genetic Research

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<sup>1</sup>STEVI, Netherlands  
<sup>2</sup>Trajectum, Netherlands  
<sup>3</sup>Maastricht University, Netherlands

The UN Convention on the Rights of Persons with Disabilities expresses concerns that there still are barriers for people with (learning) disabilities (PWLD) to participate as equal members of society. We will elaborate these concerns to the field of clinical genetics and genetic research. People with disabilities should have the opportunity to take advantage of the opportunities of modern clinical genetics. This requires careful communication about risks and desired results. We will reflect on the question who has to decide on clinical genetic testing. Further on, we will discuss the opportunities of PWLD to influence research in genetics.

## Moving from Theoretical Ethics to Applied Ethics: Management Proposal for the Police at the State of Querétaro

Lucero Itzel Oviedo-Rueda, Jose Salvador Arellano-Rodriguez  
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**Introduction:** Currently the community is on the field of normative conditioning and law of their conduct and not of the ethical dimension of human acts, but what would happen if regulation did not exist? The only way to become ethically endowed human beings is education. The police have instruments of action that are of an enunciatively nature, but their daily life requires a methodology of approach to citizens that allows them to perform their functions better, in the protection of the fundamental rights of the Mexicans.

**Justification:** In order to enable a methodology of law enforcement agencies, it is necessary to process teaching, learning and the conversion of theoretical ethics to applied ethics in their daily action, within the framework of a global situation where science advances exists; however, society seems stagnant in violence. In this scenery, ethics provides a bridge of communication between human beings, science, technology and fundamental rights to achieve a joint progress. Objective: To implement ethics training in law enforcement agencies in the State of Querétaro, to improve police work.

**Methodology:** To design and to implement a course for applied ethics training, which allows the police body to address the gap between regulation and practice, using the methodology of applied ethics.

**Expected Results:** A training course that allows police personnel to carry out their practice to regenerate the social web.

## Rawlsian Right to Abortion Access as a Case Study: Bioethics and Political Engagement

Danielle Pacia  
*The Hastings Center, USA*

Bioethics has made notable strides in effectively arguing that there is an ethical right to abortion access. However, discussions surrounding the right to abortion services rarely extend beyond a woman's autonomous right to her body or the personhood status of a fetus. While arguments rooted in personhood and autonomy of women remain persuasive within bioethics, different justifications may be necessary in order to advance reproductive justice efforts outside the academic sphere, across diverse societies and cultures. In this presentation, I will provide justification for abortion services through an alternate line of reasoning, the Rawlsian principle of fair equality of opportunity, which argues citizens in society (regardless of sex, gender, race, or economic status) should be able to access opportunities equally (as long as individuals have the same willingness and talent). Through Rawls' principle of fair equality of opportunity and Daniels' expansion of it, I assert abortion is a necessary social right because women are more equipped to utilize opportunities at an equal rate to their male counterparts when abortion services are available. Using this analysis as a case study, I will then explore implications related to bioethics generally, voting behavior, civic engagement, and advocacy.

## Children Vaccination Respect for Multiculturalism: Social Work Ethics

Adi Pachter-Alt<sup>1,2</sup>, Doron Vilner<sup>2</sup>, Nahum Michaeli<sup>2</sup>, Micha Haran<sup>2</sup>

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Social workers encounter biotic dilemmas, primarily due to social work being a non-judgmental and culture-sensitive profession that gives everyone an opportunity to QOL through faith in their powers and resources. This pluralistic approach, sometimes, encourages a gap between unique conceptions and the general social imperative. Gap that further intensifies in Israel, a multicultural country with multitude religions and streams.

One of the biotic dilemmas in Israel is childhood vaccination. According to the recommendation, most children are vaccinated, some say from the parents' view the best interests of their children and the general population. On the other hand, there are groups that refuse to vaccinate for a variety of reasons: religious belief limits; Drawing on the fact that most of the population is vaccinated; Belief in resilience and natural vaccine; Suspicion of the regulatory interests of modern medicine and more ...

In our lecture, we present the different perspectives of the dilemma and the medical social work place in attempts to mediate between individual freedom to represent the best interests of his/ her child and the protection of society in general. Linking UNESCO's Universal Declaration, Family Care and Discussions at the National Social Workers Ethics Committee.

## Global Kidney Exchange: A Case Study

Siegfredo Paloyo  
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Organ shortage is the major limitation to kidney transplantation in the developed world. Conversely, millions of end-stage renal disease patients in the developing world die because they cannot afford renal replacement therapy—even when willing living kidney donors exist. This juxtaposition between countries with funds but no available kidneys and those with available kidneys but no funds, prompts us to propose an exchange program utilizing each nation's unique assets. Our proposal leverages the cost savings achieved through earlier transplantation over dialysis to fund the cost of kidney exchange between developed-world patient/donor pairs with immunological barriers and developing-world patient/donor pairs with financial barriers. By making developed-world healthcare available to impoverished patients in the developing world, we replace unethical transplant tourism with global kidney exchange—a modality equally benefitting rich and poor. We report the one-year experience of an initial Filipino pair, whose recipient was transplanted in the US with an American donor's kidney at no cost to him. The Filipino donor donated to an American in the US through a kidney exchange chain. Follow-up care and medications in the Philippines were supported by funds from the US. We show that the logistical obstacles in this approach, although considerable, are surmountable.

## Assessment of the Knowledge, Perception and Willingness for Telemedicine Among Filipino Physicians in Different Specializations

Roland Panaligan, Samantha Alda Rojas, Jasmine Rochelle Rosita, Raphael Jommel Rosita, Louise Mari Ruiz  
University of Santo Tomas, Philippines

The COVID-19 pandemic has resulted in an ongoing nationwide community quarantine, further resulting in decreased hospital capacities due to surge in cases, work-from-home arrangements, as well as cancellation of face-to-face activities. With a fear of contracting the virus itself, health care providers have resorted to using telemedicine as a mode of consultation. This is a cross sectional study which assessed telemedicine as a medium among Filipino physicians. With the use of Google forms, a questionnaire taken from a study conducted in Riyadh by Albarak et al. (2021) was used. A total of 157 participated the study comprising of 47% males and 53% females. Attending physicians were the majority of the respondents at 86.6%. The top 3 specializations were Internal Medicine (45.9%), Pediatrics (22.9%) and Surgery (12.1%). The top online platform used was FB Messenger at 43.3%. Familiarity with telemedicine guidance was at 59.2%. Majority (42.8%) believed that telemedicine reduces healthcare cost as well as it facilitates speedy and better medical care (48.4%). However, even with its promise, there are emerging ethical considerations. About 22% of the respondents highly believe that telemedicine disrupts doctor-patient relationship. Patient privacy was said to be endangered according to almost 20% of the respondents. There is also a fear that the platform increases the possibility of malpractice in healthcare.

## Is it time for the Philippines to have a Vaccine Injury Law?

Carlo Irwin Panelo  
University of the Philippines Manila, Philippines

The Philippines introduced a mass vaccination program for dengue in 2016. When the manufacturer revealed increased risk of severe dengue for seronegative recipients, this caused a public health juror that led to the suspension of the mass vaccination program, the indictment of several government staff and private individuals, and even possibly, decline in vaccine confidence. The study attempted to establish the need for a vaccine injury law similar to that of the United States. A vaccine injury law was considered as an alternative to compensate and ensure the welfare of vaccine recipients while avoiding lengthy and costly process of litigation. The paper examines the technical rationale, legal feasibility and estimated cost of a vaccine injury law. In the context of the Philippines, a vaccine injury law can be beneficial for the Philippines. The increased fiscal space has allowed government to expand the scope and scale of vaccination programs in the past years. This increases the risk of vaccine injury in the population. However, attempts at medical malpractice legislation did not prosper in the past which could reduce the likelihood of a vaccine injury law from being passed. Legally though, Philippine constitutional mandates and jurisprudence are derived from the American legal system which implies that legal compatibility will not be an issue. The cost of vaccine injury compensation can be substantial. But this risk can be shared between parties concerned.

## Translation and Validation of the Moral Sensitivity Questionnaire in the Greek Language

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Moral sensitivity is the ability to recognize ethical challenges and dilemmas when raised, both in everyday and professional life. Within the healthcare setting, moral sensitivity is a core value and a necessary skill in order to both identify "vulnerable" patients and /or family members, and to reflect on professional actions. However, data on moral sensitivity in health professionals are scarce.

To be able to quantify moral sensitivity, an appropriate tool was searched for and the "Moral Sensitivity Questionnaire" (MSQ) developed by Lutzen et al. was identified. The MSQ-revised version was used; a short, self-administered questionnaire of 9 items covering the three main components of moral sensitivity: sense of moral burden (4 items), moral strength (3 items) and moral responsibility (2 items). The ratings of the items (6-point Likert-scale) are added, with a higher score indicating higher ethical sensitivity. The MSQ was not available in Greek, so following permission; it was translated and validated for use in Greek according to standard protocols. First it was independently translated by two researchers, a common translation agreed and that version was back-translated to English by a third researcher and compared to the original. Finally, it was validated by test-retest in 10 students one week apart.

## Striking the Mother Lode in Islamic Bioethics

Dilkush Panjwani  
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Abundance of ignorance about Islam has created a negative perception of Muslim ethics, values and law in the minds of many people around the world. This paper aims to highlight Islamic concept of righteousness, calling on believers to seek a way of life with a social conscience. Most faith traditions, including Islam, deal with universal questions: Why must I act ethically? What is right and wrong in the real world? How should I act in a given situation? What tells me that I am on the right path? This paper explores the roots of Islam's ethical framework about what is right and benevolent. Muslim healthcare bioethics is closely linked to the teachings of the Qur'an and the Prophetic tradition – an integral part of the religion itself. It underscores the continuum of the body and mind, the material and the spiritual, ethics and jurisprudence. In Islam, life is sacred and every stage of human life is valuable. Muslim doctor has a duty to protect human life in all stages and under all circumstances. Muslim luminaries and scholars have reflected on medical bioethics and discussed the four key principles of modern day bioethics – autonomy, beneficence, non-maleficence and justice. In recent years, Muslim jurists have discussed and sought consensus on matters of assisted suicide/euthanasia, organ transplantation, genetic testing, human embryonic stem cell research, informed consent, end of life decision-making, assisted reproduction and abortion.



## Informed Consent and the Application of the Principles of Montgomery: A Critical Review

Maria Paraskeva  
Cyprus

Four years after the Montgomery landmark judgment, this presentation aims to critically review the application of the principles of Montgomery; whether it has been followed in future cases by courts and if it has influenced the everyday medical professional practice. For this reason, Montgomery case, will be the subject of analysis of the basic principles applied to consent in the context of information disclosure. Yet, the major concerns will be identified and analyzed through subsequent case law and relevant literature. I will conclude that courts have not strictly followed the application of the principles that Montgomery manifests, and that medical practice is already changing towards a more patient-focused approach. The impact of the decision, for the time being, has limits and the implementation of Montgomery principles in both the legal and the medical ground has been slow and patchy. I argue that the law has come a long way since the time it refused to acknowledge the patient's rights. Thus, the days of the doctor 'knows best' belong to the past. Much can be gained from a shift towards a more person-centred perspective and despite its criticism, Montgomery is a welcome development of the UK law.

## Law, Technology and Health: A New Paradigm Needed?

Maria Magnolia Pardo-Lopez  
University of Murcia-UMU, Spain

For several years a new paradigm, "Precision or Personalized Medicine", has been presented in various forums and conferences. The arguments of weight and the undeniable reality that have revolutionized Medicine were slowly penetrating in the Parliament until in 2018 a quality debate on health began. The Spanish Senate is working with the best experts from different disciplines to configure a map of the challenges that the country must face to draw up a Personalized Medicine Plan. The word "Plan" is associated with a budget. One of the latest developments is the need to guarantee optimal access to this new kind of Medicine. To this end, experts have transferred to the senators the option of centralization of laboratory technology and the standardization of processes. They also understand that early participation in clinical trials is a quick way to get their availability after the approval of the European Medicines Agency.

Bioethics has also been one of the main protagonists of the report on Genomics. This paper aims to deepen on the compatibility or incompatibility between respect for human life or the therapeutic principle, on the one hand, with the handling of a large volume of health data that facilitate the right decision making, on the other hand.

## The Invisibility of Psychiatric Nursing and its Consequences on Human Rights: A Discursive Analysis of the Jurisprudence of the Province of Quebec, Canada

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The invisibility of nursing practice is a phenomenon that has been extensively documented over the past decade. This phenomenon can be described as a lack of recognition of nurses' organizing work in order to maintain the integrity, continuity and safety of health care. This work is particularly important in psychiatry, particularly when the health and judicial systems intersect, although no study has documented its core characteristics and their numerous ethical and legal implications. We conducted a discursive analysis of the jurisprudence of the province of Quebec, Canada, concerning (1) involuntary hospitalization or treatment, and (2) care offered to persons under the authority of an administrative tribunal who have been found not criminally responsible for their actions. The aim of this study was to document and explain the role of nurses in the context of psychiatric coercion, as well as to situate them on the continuum of care. The analysis of the results is based on the Translational Mobilisation Theory (Allen & May, 2017). The results confirm the invisibility of nurses' organizing work. They also suggest the important role they play in supporting the exercise of human rights in psychiatry, whether by collecting information on users' behaviors, contributing to the assessment of psychiatric risk or informing users of their rights and legal procedures. Empirical studies are urgently needed to determine if this role is misrecognized among nurses themselves.

## Advance Directives and Dementia: Self-determination, Utopia, Critical Issues

Carlo Pasetti  
Italy

The A.D. enhance the patient's self-determination, and their validity is unexceptionable; however, when we introduce them into the clinical practice many uncertainties arise, especially in advanced stages of dementia. The lack of competency and the impossibility of expressing a Consent explain why the requests for euthanasia in dementia are rare. In this respect, we find distinctive the issue of personal identity, a factor on which there are two opposing viewpoints:

A: the person in the advanced stage of dementia is the same person who expressed the A.D., safeguarding the latter we protect the patient's critical interests and autonomy.

B: the present interests should prevail over the previous ones, especially in patients with a fairly good QoL and relationship capacity, safeguarding their best interest with which the A.D. could contrast.

The ethical dilemma is excruciating, although the choice falls on the patient who is unable to express him/herself. Should we protect the patient of then ("then self"), respecting his/her autonomy or should we protect the patient of the present ("now self") out of principle of beneficence?

Deciding for others becomes impossible without ethics, although the use of rating scales of decision-making competency together with the caregiver's opinion could help balance autonomy and beneficence. Since there are numerous critical points in the application of the A.D, it appears fundamental to train doctors not only as clinical but also as moral agents.



## Assisted Reproductive Technologies & Overpopulation

Chantal Patel  
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Assisted reproductive technologies have given hope to millions suffering from infertility. Yet there is widespread concern about world overpopulation. And, despite the overall trend of population growth, fertility levels and rates are dropping, increasing the demand for ART. So, given the concern regarding overpopulation would it be ethical to limit the availability of ART? If so, how should it be implemented? Notwithstanding the emotive issues of ethics, equity & practicability, I conclude that a utilitarian approach may be ethically appropriate as a justification for placing limitations on the availability of ART. Admittedly, a utilitarian approach is not without issues, given that it adopts a position that ignores all but the greatest good for the greatest number. Nevertheless, there is a strong case for a utilitarian solution as it supports the saving of the planet above personal rights to procreation. Clearly there are competing interests here: the need to safeguard the planet & its existing inhabitants and the infringement on the right of the individual to procreate. However, while acknowledging this, together with the practical difficulties, I propose that it would be ethically acceptable to place limitations on the use of ART.

## The Future of Genome Editing

Shaun Pattinson  
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There are only two international instruments on the protection of human rights in the biomedical field: the Council of Europe's Convention on Human Rights and Biomedicine and the Universal Declaration on the Human Genome and Human Rights. Both have provisions relevant to the genome editing of embryos, but they are now 25 years old.

Jiankui He's attempt to genome edit embryos for HIV was contrary to these two international instruments. In this paper, I discern support for three norms from these instruments: (1) rejection of genome editing of embryos, (2) rejection of use for the purposes of enhancement and (3) requiring beneficial clinical uses to be made available to all. I ask whether these norms would be defensible if the technology develops to the point at which the biomedical risks to the edited embryo are rendered negligible.

If the technology becomes suitably safe, a key concern would be that access would be likely to perpetuate and magnify socio-economic inequalities. I will argue that all three discerned norms could be understood as responses to this concern, but they all have potentially disproportionate effects.

## Ethics Education Role in Stem People Preparation

Ioannis Patias  
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Engineers, and people with so-called STEM (science, technology, engineering, and mathematics) background and education usually do not have philosophical or ethics education. They are not familiar with the concepts and terminology used by philosophers and ethicists. The aim of our research is to explore the necessity of introducing philosophy and ethics-related courses in STEM education curricula. No system can or should be neither blind trusted nor blind distrusted. Students of STEM courses need to learn how to create, deploy, and operate autonomous and intelligent systems (A/IS), which can be trusted.

In the University of Sofia "St. Kliment Ohridski", Dept. of Mathematics and Informatics a new discipline was introduced. In the discipline the IEEE initiative on ethically aligned design, and the EU guidelines for trustworthy artificial intelligence are presented, discussed and also covered in a practical manner. We use a project-oriented approach, which aims to provide the students apart with strong theoretical background, also with real practical instruments and experience on their use. A/IS's trustworthiness is a key factor for this transformation. STEM people produces A/IS cannot be trusted if they produce outcomes for which it is unclear or even does not exist assigned responsibility.

## Intention of Organ Donation in an Adult Population Sample from the City of Sao Paulo

Angela Pecci, Leandro Silva, Leonardo Bernardo, Edson Umeda  
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**Introduction:** Brazil is the second largest organ transplant country in the world. However, the amount of organs from donors in brain death is below the necessary. The number of effective donors increases between 2 to 3% annually while the number of family denials maintains at approximately 43% since 2017; most of those denials derive from the lack of knowledge about the subject from the general population.

**Objective:** To analyze data about the intention of donating organs post-death in a population sample from the city of Sao Paulo and verify their basic knowledge about brain death.

**Methodology:** Field research; observational, descriptive, cross-sectional study, performed through a modified survey taken in public parks and squares in the city.

There were 614 participants, in which 72.8% intend on donating organs after death, while 90.8% would accept receiving a transplant; 79.3% don't know what brain death is or do not comprehend the concept of its diagnosis.

**Conclusion:** It's evident the lack of knowledge from the general population regarding the process of organ donation, even though most seem altruistic and good-hearted. Therefore, it's crucial to develop educational actions to increase awareness about the irreversibility of brain death's diagnosis.

## Death and Dying: Similar or Different Perspectives in Palliative Care?

Alexandra Pedruco<sup>1</sup>, Talita Moreira<sup>2</sup>

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Psychological interventions must meet the specific requirements of palliative care.

Grief begins when a family knows that their child's health is threatened. Grief support is fundamental in the process of care and after the death of the child. Psychological interventions are adjusted by the family dynamics as it changes and suffers new challenges. An interdisciplinary care team should give family-centered grief support. The child, siblings and parents' emotions are the focus of palliative care in a psychological perspective.

The aim of this communication is to present different micro realities in two countries - Portugal and Brazil, by two clinical psychologists of also different generations and backgrounds.

Clinical cases are being presented to illustrate psychological intervention.

## Health Inequalities and Protection of Dignity in the End of Life

Elmantas Peicius, Gvidas Urbonas

LUHS, Lithuania

The protection of human dignity is still one of the core issues in bioethics. Despite the criticism, dignity remains the main prerequisite of development of just welfare society. A number of previous studies revealed the significant determinants for ensuring the dignified end of life of terminally ill persons. Inter alia, the most vulnerable members of society may encounter existential inequalities (Therborn, 2013) such as unequal distribution of autonomy and respect, limitations of freedom and communication with relatives, unequal distribution of resources, inequalities in incomes, or unequal distribution of health care access. This paper aims to discuss the major health and social inequalities that have been determined during the recent qualitative studies in Lithuania. The challenge to ensure a dignified life becomes particularly relevant when a person becomes physically, socially and morally vulnerable due to age, serious or incurable illness or other restrictions of normal life, or loss of human identity for economic reasons. The reported existential inequalities include premature death or morbidity to unequal life chances, lack of confidence, powerlessness, and other that might negatively affect the implementation of the imperative of protection of dignity. The preliminary guidelines, based on the identified needs, expectations or barriers will be argued.

## The Clinical Ethics Consultancy Service at Bnei-Zion at 7 Years: Empirical Insights

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<sup>2</sup>University of Haifa, Israel

The Clinical ethics Consultancy service at Bnei-Zion Medical Center was founded at the end of 2012, and became fully operational (as well as systematically documented) by 2014.

During the years 2014-2019 (up-to 10/2019) the service was involved in 1502 separate consultations (ranging from 214 consultations in 2014 to 296 in 2018), via multiple consultation-platforms, which included 1) telephone consultations 2) e-mail consultations 3) writing of guidelines 4) on-ward consultation and 5) ethics committee meetings.

Fifty-three of the Center's wards, departments and services have utilized the ethics consultation service – at variable scopes, as well as on much varied topics.

In this presentation I will review the ethical needs of Bnei-Zion Medical Center, and attempt to extrapolate from it on to the ethical needs of general hospitals in Israel (as well as maybe in other national-health-care-services countries) in general, while focusing on the following questions:

1) What departments/services are most in need of (or most utilize the) ethics consultancy services?

2) What type of issues most commonly cause ethical stress amongst health-care personnel, driving them to seek ethical advice?

And finally,

3) What factors serve to hinder or to derive the use of the ethics-consultant's services.

## Ethical Considerations Emerging from a Realist Synthesis of Interventions aimed at Reducing HIV-Stigma in Healthcare Settings

Jérôme Pelletier<sup>1</sup>, Johanne Hébert<sup>1</sup>, Dave Bergeron<sup>1</sup>,

Geneviève Rouleau<sup>2</sup>, Laurence Guillaumie<sup>2</sup>

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Previous systematic reviews have shown that interventions aimed at reducing HIV-stigma in healthcare settings have limited and sometimes contradictory effects. A realist synthesis of these interventions is underway in order to develop a program theory that supports the development of nursing practice aimed at mitigating the impact of HIV-stigma. Preliminary results raise ethical questions. Interventions are mostly based on PLHIV perspectives of stigma. Their beliefs about variables to be targeted (e.g. "nurses' attitudes" or "nurses' knowledge") and about the strategies to be used to change these variables generally shape interventions' design. Other psychosocial variables capturing nurses' perspective about stigmatization (e.g. norms, role models or professional education) are often neglected. Considering the limited effects of these interventions, one may question to what extent PLHIV perspectives about stigma should contribute to their development in comparison of nurses' perspectives. On the other hand, an intervention aimed at reducing HIV-stigma would not be ethical without the involvement of PLHIV in its development and implementation. By focusing on underlying theories instead of effect size of interventions, the realist synthesis underway has the potential to enhance the contribution of both perspectives, while recognizing the unique value of PLHIV and nurses' experiences of stigma.

## Socio-Cultural Competence and People-Centered Clinical Trials: An Urgent Need for an Ethical, Effective and Collaborative International Research

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According to the 21st article of the 2005 UNESCO declaration on Bioethics and Human Rights, "transnational health research should be responsive to the needs of host countries," and in a research agreement "the benefits of research should be established with equal participation by those party to the negotiation." Unfortunately, various declarations and guidelines, born in the light of the fundamental ethical principles of autonomy, beneficence, non-maleficence and justice, had been transformed into norms and laws only in the so-called "developed countries," leaving the rest of the world as a hunting (exploitable) ground to advance the mere interests of the pharmaceutical industries and research sponsors. Cultural and linguistic differences, poverty, illiteracy, limited resources, education, health-care services, and lack of experience or familiarity with research, resulting in poor understanding of its scientific nature, expose developing countries to a high risk of exploitation, notwithstanding that, taking part in clinical trials represents, sometimes, the only chance to access medical treatment, or gaining health benefits. Vice versa, clinical research with human participants should be tailored on a study-by-study basis, respecting the therapeutic needs and wishes of the local community, in consideration of the pros and cons of each type of research. Cultural responsiveness, awareness, and sensitivity is needed to promote an ethical, effective and collaborative international research with human beings, placing clinical trials' participants' rights, safety and well-being over the interests of science and society, instead of the ongoing trend of globalization, where industries' profits and governments' businesses are often neglecting and sometimes overwhelming any kind of communities' and personal respect.

## Hippocrates Tears: Death by Medicine

Deborah Kala Perkins

EuBios Institute, AUSN, USA

"You are turning medicines into poisons, like cocaine"

We deal with ecocide, the murder of nature, life's healing and health properties, needing to wake up as a race." Amazonian Medical Practitioner.

When medicine becomes the illness, the proposed solution, the disease, we are in a systemic bioethical crisis. Pharmaceutical industries have become a megalithic with their own economic agendas (\$656 billion, 2018), and consumers their dumping grounds and prey. Average US elders consume 5-7 prescription drugs, (@\$450), with adverse drug reactions accounting for 15% of all hospitalizations. Warning labels may read: "May cause dizziness, headaches, hypertension, drowsiness, vomiting, heart palpitations, irrational behaviors, seizures...bouts of unconsciousness. Consult your physician if these persist". Yet such 'medications' are prescribed copiously by doctors sadly puppeteer by pharmaceutical industries. Children 2-4yrs. are being prescribed drugs, supposedly for hyperactivity (ADHD). Removed from the drug wheels patients often fair better. The US has an opioid addiction epidemic:

"More than 70,200 Americans died of drug overdoses (2017), including illicit drugs and prescription opioids - a 2-fold increase in a decade", largely initiated by pain prescriptions. US consumes the majority of drugs produced, at the roots of much of its Central American refugee crisis. This talk analyzes relevant bioethical dilemmas.

## Ethics, Deontology and Professional Responsibility as a Common Denominator for the Health Professionals

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The projects 'Ethics, Deontology and Professional Responsibility as a Common Denominator' and "Ethicare" were launched in 2019 by the National Federation of TSRM PSTRP Registers, an organization born in 2018 to bring together 19 previously separate Health Professions (HPs). In a fruitful moment for healthcare research and innovative technologies, the Federation's Code of Ethics has the ambitious goal of revisiting and safeguarding the founding principles of the National Health System: Universalism, Egalitarianism and Solidarity, investing the rights of people and their relationship with the HPs.

A professional who asks to be registered in his own Professional Register should share with other professionals in other Registers, in addition to a Single Ethical Code, a single Declaration of commitment to transform nouns into actions.

The Ethical Charter must be known both to professionals and to the citizens with information campaigns on multiple platforms.

In this sense the Federation acts as guarantor of practices reflecting the evolution of science, technology, digital healthcare and big data while also considering the dilemmas of the ethical and bioethical fields.

The project aims to be a "permanent laboratory" within which we can face and overcome the critical issues that society presents us from time to time through "doing", in compliance with ethical principles.

## Covid and Prison: The Italian Experience

Giulia Petroni, Jacopo Giammatteo, Michele Treglia,

Margherita Pallocci, Luigi Tonino Marsella

Università degli Studi di Roma "Tor Vergata", Italy

Ensuring safe conditions of inmates is a constitutional and ethical obligation. During the most contagious phase of COVID-19 pandemic, the Italian Government has established a series of measures aimed to contain and manage health at prisons. In addition to general precautions for infections prevention, isolation and quarantine of suspect cases, suspension of visits from relatives, operators and lawyers, in order to limit external contacts with detainees, further measures have been ordered to reduce overcrowding. On 29th-February-2020, there were 61.230 prisoners in penitentiaries with a maximum capacity of 50.931 people, which resulted in an occupancy level of 120,22%. The Legislative Decree n. 18/2020 ordered the release of older prisoners with previous comorbidity, of those with a minimum remaining sentence to be served and of those detained for minor or non-violent crimes. Thanks to legislative intervention, on 31st July 2020, the occupancy level in penitentiaries dropped by 14,7%. Despite the impossibility of applying social distancing regulations, in phase-1 of the pandemic, in Italian prisons the spread of coronavirus has been contained. Given the good results achieved, the same strategies adopted to contain the pandemic can be ordinary applied to reduce overcrowding, which is a known risk factor for the health of prisoners.

## The Patient Capability of being Part of a Medical Services Contract

Mariya Petrova  
European Institute of Healthcare Law, Healthcare Management  
and Public Health, Bulgaria

The purpose of this development is to address the legal and ethical challenges that patients face when negotiating contracts for health care and medical services.

In today's fast-growing life, medical services are increasingly being presented as a consumer or as commercial services. This places the patient in the role of a customer or consumer. Medical service contracts contain their specifics and in order to be able to properly evaluate their effectiveness and to develop their application, attention must be paid to their terms.

The condition of patients is almost always such that they are not able to freely and adequately negotiate terms in their contracts, which puts them under duress and causes a restriction of free will and freedom of contract.

On the other hand, restrictions, and requirements like malpractice clauses, the processes of informed consent and informed choice, patient needs and suggestions from healthcare providers can become a growth stopper to many medical services such as medical tourism, transplantation, surrogacy, the use of implantable medical devices, aesthetic interventions, gender reassignment, and others.

This report is addressing the legal and ethical challenges of global dimensions, as well as the advantages and disadvantages of the negotiation process and the option of pre-contractual liability for patients when they are a party in a health care and medical services contracts.

## The Importance of Functional Health Literacy in the Informed, Free and Clarified Consent in Genomics

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To participate in research and procedures in genetics and genomics, there must be informed, free and clarified consent of the volunteer / patient. However, the information to assist in decision making should, according to CEP / CONEP system recommendations, be clear and simplified to make the understanding effective. Functional Health Literacy and Literacy in genomics concepts should be considered in the elaboration of the consent terms, in the conception of graphic materials, interviews and verbal communication, so that the individual can evaluate the transmitted information and decide with full autonomy. Thus, the paper aims to identify the problems in the application of these documents and their effectiveness in Brazil, considering the understanding of the volunteer / patient. A bibliographic survey will be conducted on how informed, free and clarified consent for research and procedures in genetics is presented in different countries for comparative purposes; semi-structured interviews will be conducted with researchers and genetic counseling professionals; and, a script proposal will be formulated for the elaboration of these documents, taking into account the principles of functional health literacy, aiming at clarification in genomics.

## Duty to Care vs. Duty to Self: Call for Guidelines for Collective Actions by Health Care Providers

Sharad Philip, Avinash Shekhar, Prabhu Jadhav  
NIMHANS, India

Collective actions by professionals including strikes are aimed at highlighting the importance of services through disruptions. The extent of disruption is linked to gaining the upper hand in negotiations for the desired outcome. Society deems collective actions by doctors and nurses to be less than acceptable. Split opinions on the ethical and moral justifications for such actions exist. Antecedent causes, demands and/ or the means of collective action determine ethicality and morality. The necessity of continuing emergency services is a pervasive theme noted in all collective actions. The International Council of Nurses (ICN) has issued clear guidelines on industrial action. Position statements from World Medical Association (WMA) exist providing a vague framework which reminds doctors of their ethical and professional obligations. The WMA stance appears to distance itself from collective actions, but their stated commitments are towards providing ethical guidance for National Medical Associations (NMAs) and physicians.

More is required in terms of support for collective action so as to reduce their need. We suggest clarifications from WMA on collective action by member physicians. We call for the issuance of clear guidelines as to how, when and what collective actions can be carried out by physicians worldwide.

## Ethical Best Practice in a Collaboration between an Embassy and an Offender Healthcare NGO in Advocating for their Sick Citizens Imprisoned in a Resource-Poor Western Pacific Country

Rachael Pickering  
Integritas Healthcare, UK

The author recalls the development of a collaboration between the offender healthcare NGO and a European country's embassy in a resource-poor Western Pacific country. Her role in this collaboration is as medical director of the NGO. And the collaboration seeks to benefit the health and wellbeing of any citizen from the European country who finds himself/herself detained in one of the host country's secure environments.\*

The author then presents condensed case studies: in the majority of cases the citizens' health improved as a result of the collaboration, but in two cases the citizens subsequently died whilst still detained.

Next, the author presents an overview of a literature search about such collaborative work.

And finally, the author proposes a set of guidelines for ethical best practice in such collaborative work.

\* The identities of the European country and Western Pacific country may be revealed during the oral presentation. Permission for identification has been sought from the embassy's consul and a decision is pending; however, permission has already been granted for this collaboration to be discussed in anonymized form.



## Healthcare Care Proxy in Poland: Are the General Laws of Representation Sufficient?

Albert Pielak  
University of Warsaw, Poland

As there is no specialized regulation of healthcare proxy in Polish law, it may be asked whether the existing provisions concerning representation are capable of accommodating this peculiar legal category. The Polish Supreme Court in resolution of 13 May 2015 (ref. number III CZP 19/15) opined that the patient may grant a power of attorney to consent to a medical intervention, basing on general rules of representation. It has to be mentioned that civil law does not recognize the common law principle - "automatic revocation rule".

The crux of the debate is the correct interpretation of Article 95 § 1 of the Civil Code, under which, subject to exceptions provided for by statute or resulting from the nature of a juridical act, a juridical act may be carried out through a representative. It is worth pondering whether medical consent should be classified as a personal legal act in civil law systems. It needs to be highlighted that the Roman law provenance of the concept of power of attorney is of a property character. Doubtless, application of laws concerning power of attorney to non-property relations (e.g. medical treatment) is problematic.

Author will consider whether basing on the healthcare power of attorney upon the general laws of representation is sufficient to guarantee adequate protection of constitutionally protected values. The paper will include comparative law remarks, which could be useful for civil law systems without health care proxy provisions.

## Dignified Incarceration: Humiliation, Denials of Opportunities, and Death

Bryan Pilkington  
Seton Hall University, USA

I argue that the dignity should play a role in moral analysis of health-related issues associated with incarceration. There are two initial challenges to such a proposal. First, dignity has a fraught history of employment in bioethical theorizing, often being rejected by thoughtful critics due to concerns of consistency, problems of clarity, and basic disagreements about dignity's role in ethical theorizing. Second, though invoked in some popular and academic discussions of incarceration, dignity's appeal is not widespread (compared with, for example, considerations of autonomy or rights of various kinds). In the first part of the paper, I address these challenges. Next, I rely on the work of novelist and playwright John Galsworthy to motivate and account of dignity. Third, I highlight a tension with the concept that reflection on Galsworthy's work gives rise to and, interestingly, which is tracked in work from other fields on dignity. Finally, describe three instances of indignity – denials of opportunities, humiliation, and killing – and the normative implications of taking dignity seriously for the health of persons who are incarcerated. Reflection on dignity and instances of indignity suggest changes to health-related practices in prisons which might allow for greater resilience for incarcerated persons.

## The Impact of The Terminology on the Acceptance of Palliative Care in Breast Cancer Patients

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Palliative Care referral is recommended at the moment of diagnosis aiming at more effective symptom management and suffering reduction. However, it has been shown that, in cancer patients, referral to Palliative Care takes place mostly during the final phase of the disease, when there are no treatment options with curative intent. One of the reasons identified as contributor to this reality lies in the very term "Palliative Care", often associated with the idea that it is a resource only directed towards end-of-life care, constituting in it a source of hopelessness, restlessness and suffering. This study proposes to characterize, in breast cancer patients, the stigma associated with the term "Palliative Care". We will evaluate whether literacy, ECOG score, date of diagnosis, staging, previous treatment, current follow-up, the relationship with the doctor, and the patient's expectations about the treatment carried out have any influence on the stigma associated with the term "Palliative Care".

A prospective cohort study was designed to include breast cancer patients followed at the IPO-Porto. The questionnaire to apply is crucial to the understanding of determinants of the stigma and will allow to design strategies to overcome it.

## Palliative Care in Mozambique: Knowledge, Attitudes and Physicians' Practices in Breaking Bad News and End-Of-Life Issues

Emília Pinto<sup>1</sup>, Gustavo Marcos<sup>2</sup>, Camila Waltes<sup>3</sup>, Ferraz Gonçalves<sup>4</sup>, Jahit Sacralal<sup>2</sup>, Luisa Castro<sup>5</sup>, Guilhermina Rego<sup>1</sup>

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**Introduction:** Palliative Care (PC) remains limited, inaccessible or even absent in developing countries.

**Objective:** to evaluate the knowledge, attitudes and practices of Mozambican's physicians in Breaking bad news, and end-of life issues.

**Methods:** A cross-sectional study was conducted between 08/2018 - 01/2019 to physicians in 4 hospitals in Mozambique. Data was collected by a questionnaire and analyzed with SPSS. (25)

**Results:** From a total of 306 physicians, 207 answered the questionnaire. The median age was 38 years, with 9 years of working experience. There was a predominance of females, resident physicians and surgery specialists. Seventy three percent of the participants informs the patient about the cancer's diagnosis; 60.1% prefers to inform the diagnosis and prognosis to the family / caregivers; 50% knows what a do-not-resuscitate order is, and 51.3% know what palliative sedation is. Only 24% of them knew all answers about euthanasia and related issues.

**Conclusion:** In Mozambican paternalism and the family-centered model is the most prevalent. The decision making is based on medical ethical principles. There is a need for training and integration PC in the curriculum of health professionals.



## Health Inequity: A Tool of Political Denunciation

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The Argentine Constitution acknowledges the Right to Health as a human right to be guaranteed (Article 14 and 14 bis). Government Officials swear that they obey and enforce the law.

But reality shows inequity in a complex, fragmentary health system. There are five sectors in the population (Union Health Insurance 33%, No Health Insurance 32%, Provincial Health Insurance 14% Prepaid Private Health Insurance 12 % and Health Insurance for Retired People 11%). The economic resources of each sector are very different - the Free Public System having the least and the Prepaid Private Health Insurance having the most (difference 240%).

30% of the patients who are given health care in the Free Public System have health insurance of any kind, thus damaging the poor people in the Free Public System.

The rates of mortality in children (e.g. Buenos Aires City 8/1,000 , Corrientes 16/1,000) and mothers (Buenos Aires City 3/100,000 born alive , La Rioja 16/100,00) (Official Report 2016) are examples of the inequity featuring our health care system.

Although the Government contributes by paying less than 10% of the overall health costs, there are neither centralized targets or planning nor regulations for medications or critical supplies – a breach of the Constitution.

## At the Bedside: Implementing the Concept of Shared Decision Making

Miriam Piven Cotler  
CSUN, USA

The ethical concept of shared decision making assumes common goals directed toward the person in the bed whom we term the "patient". However, differences within and between professionals, patients and families with respect to agendas, understandings, knowledge and skills are further complicated by personal history, values, and goals. These differences impact the process and outcome of care. This discussion attempts to organize major commonalities and differences and describe some of the concerns driving parties, with recommended strategies to obtain decisions consistent with the patient's goals, best interests, and clinical appropriateness. It explores both structure and process. How do structural changes support or disturb relationships among participants? E.g., Does "shared decision making" presume a level playing field? We acknowledge that the patient is more vulnerable, yet we are often not clear about how identify and address their concerns. How to establish trust? Is there a process for addressing cultural differences? How much information is adequate, and what if the patient wants to know less? Physicians and other members of the clinical team may not be in agreement or clear about the patient's values. How comfortable are physicians acknowledging uncertainty? Clinical ethics consultations must acknowledge these potential roadblocks to authentic, respectful decisions.

## Organ Trafficking: The Portuguese Experience in Developing a Legal Framework and a Code of Conduct for Healthcare Professionals for the Management of Patients and Report Suspected Cases to Law Enforcement Authorities

Ana Pires Silva  
Instituto Português do Sangue e da Transplantação, Portugal

The existence of a world-wide illicit trade in human organs for the purposes of transplantation is a well-established fact, and various means have been adopted to combat this criminal activity, in particular the recent Council of Europe Convention against Trafficking in Human Organs. This Convention is the first international legal instrument that criminalizes all illicit transplant practices. Healthcare professionals who treat patients in pre transplant and post-transplant play a crucial role in prevention, detection and reporting organ trafficking. However, healthcare professionals face with medical, legal, and ethical problems when confronted with suspected or confirmed cases of organ trafficking due to their duty to preserve medical confidentiality. We present the recently developed Portuguese Model for the implementation of the Convention against Trafficking in Human Organs. First, we present the legislative changes that are occurring, such as the framework developed to allow healthcare professionals to disclose information on organ trafficking. Secondly, we present a code of conduct developed for healthcare professionals to address such challenges and provide guidelines for the management of those patients, including indicators to identify suspicious, and a reporting mechanism for the communication of suspected cases of organ trafficking to law enforcement authorities for the purposes of criminal investigation.

## Making Ethical Decisions in Biopharmaceutical R&D: Sharing Experience of the TRIP & TIPP Model

Tatjana Poplazarova, Claar van der Zee, Thomas Breuer  
Vaccines' Office of Medical Governance and Bioethics- GSK, Belgium

Frameworks and models to support ethical decision making exist and are much studied in various disciplines, ranging from business management to clinical practice. Yet there is limited evidence for the existence and application of systematic methods for resolving ethical questions that arise in the context of biopharmaceutical research and development (R&D) activities. We have developed "TRIP & TIPP", an ethical decision-making model that incorporates company values as part of a five-step process. TRIP & TIPP engages employees as moral agents, systematically guiding them through applying principles to reach an optimal outcome for the situation in question. Real life case studies show the model being used in practice. Early results, via employee feedback on their experience using TRIP & TIPP within their teams, suggest high acceptability and usefulness of the model. Our experience with the model is in an R&D context whereby employees are empowered to use their judgement, after training in workshops using case studies, but it could also be applied in other areas.

## Dealing with Ethical Dilemmas in Geriatric Patients through Multi-disciplinary Team Work

Tammy Porat-Packer, Eti Shitrit  
*Technion - Israel Institute of Technology, Israel*

The growing geriatric population and modern medical technology, challenge medical teams in the way they deal with ethical dilemmas in this age group. These dilemmas are created when there are contradictory ethical principles. The goal is to choose the appropriate treatment for the patient while maintaining his right to autonomy, granting him quality of life and bearing in mind his wishes. In order to implement this approach in geriatric hospitals, multi-disciplinary teamwork is of vital importance.

Take the example of an extreme case of a 65-year-old-female patient with no name, destitute and living on the streets with no family. She was on regular hemodialysis and on admission had infected skin ulcers. She was non-compliant with medical and nursing care, except for dialysis treatment. An extended multi-disciplinary team performed an ongoing evaluation in order to assess her medical, functional, cognitive and mental status.

The patient was found to be cognitively sound and had proper judgment. She was independent in her wheelchair, exhibited extremely poor personal hygiene and demonstrated verbal and physical violence. She was actually a risk to herself and her surroundings. It was decided that "her way" should be respected - but it cost her life.

## Jameton's Definition of Moral Distress: A Philosophical Study

Alana Prashad  
*University of British Columbia, Canada*

**Situation:** There has been a call of late for the study of the philosophical underpinnings of moral distress. Philosophical articles reviewed consider moral distress within the very moment of moral distress experienced by the clinician.

**Background:** In the last 35 years, studies have focused on quantifying moral distress with the development of the Moral Distress Scale. Solutions offered often cite a robust ethical climate within which clinicians feel safe to air their distress. Increasingly qualitative or hybrid studies seek to understand moral distress beyond ICU nursing including fields such as social work, policing, and teaching.

**Assessment:** Despite decades of studies, moral distress continues to confound frontline practice and response thereof. The Moral Distress Map points to a promising practice of self-reflection guided by the map and a clinical supervisor. This philosophical study takes a turn inwards towards Jameton's definition of moral distress itself examining the very words within the definition.

**Recommendation:** The philosophical pedigree of Jameton's definition is best appreciated by the very words themselves once seen through a framework including Hannah Arendt's "vita activa" and "vita contemplativa" and Aristotle's "phronesis" and "soul". The concepts "one", "absence" and "soul" are offered reveal a deeper call even beyond healthcare.

## Shared Decision-Making Model and Resignification as a Strategy for Bioethics Consulting

Paula Prieto Martínez, Nathalia Rodríguez Suárez  
*Fundación Santa Fe De Bogotá, Colombia*

Bioethics, as an inter-knowledge mediator, allows agreements to be reached in these situations. A fundamental model in this task is shared decision-making. This model claims the role of each participant in this meeting, without giving greater weight in the balance, for example, to medical knowledge or the desire of the patient, and allows to understand the relationship that is established in the meeting in health as one that requires joint participation.

The shared decision-making model is complemented by a constant tool in the work of the Humanism and Bioethics Service: resignification. When there are moments of tension in the professional meeting of health-patient/family seem to give themselves misperceptions, from the patient and his family in what treats medical treatments and, from the health care professional, in what is beneficial (2000) to the patient. This process is what we call resigning from the Humanism and Bioethics Service, an excellent and necessary complement to shared decision-making.

## Reproductive Biomedicine and European Public Policies, Human Genetics and Biomedical Evolution, Surrogacy: The Impact of Legislation on Medicine

João Proença Xavier<sup>1,2</sup>  
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This Study, about subrogated maternity, wants to put out a brief commentary concerning the natural impact on Law of the new reproductive possibilities brought out from new Medically Assisted Reproduction techniques, through the comparative of RMA European legislation on surrogacy, which is nowadays suspended in the Portuguese case, creating social and medical impacts that, in the eye of a jurist, will give indication they (society and medical community) are not actually prepared for...

## The Right to Die as a Hohfeldian Immunity

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While its counterpart, the right to life, recapitulates concepts that are intuitively intelligible and much keener to our moral sentiments, and therefore less vulnerable to criticism as less likely to be challenged or questioned - prima facie at least, the situation is quite the opposite when it comes to the right to die, since death is the negation of life and, therefore, the complete annulment of any right. On the other hand, while the concept of moral rights is considered to be the crest of rationality and rational moral humanity, death is by definition a scandal for reason, and scandals can be resolved only by faith, religious or other. In the light of the above, it is often suggested that a putative 'right to die' could only be counted as a textbook case of a contradiction in terminis, since it makes appeal to an impossible connection: it sets out to harmonize what is by definition irrational and incomprehensible with one of the most remarkable fruits of rationality. Against this view in this presentation, I will argue that the right to die could be justified in the case of passive euthanasia as an autonomy related negative right – or, an immunity, according to Hohfeld's classification of rights.

## Cyborgs: Human Body, Technological Devices and Freedom

Marc-Abraham Puig Hernández  
University of Barcelona, Spain

Cyborgs open a debate about the use of technological devices. Concretely, how to integrate them into human body. My hypothesis is this use can contribute to equalize freedom, in contrast with any particular purpose which we would identify with personal autonomy. This distinction has place in the Ethics of Human Enhancement; therefore, Law cannot remain impassive.

Firstly, I use the concept of technological device instead of medical device, which appears in Regulation (EU) 2017/745 of the European Parliament and of the Council. The former concept describes better the concept of cyborg as a hybrid organism, composed by organic and technological parts.

Secondly, on distinguishing freedom and autonomy, I rely on human nature and "equal human capabilities" to explain that there are social reasons to justify an integration of technological devices into human bodies. Any other justification would not have grounds on the human enhancement discourse.

Finally, I have tried to apprise how this matter should be regulated considering the justification given.

## Being a Donor has Definitely Given Me Something: An Empirical Ethics Analysis of Egg Providers' Motivations and Gains

Veerle Provoost<sup>1</sup>, Catherine Coveny<sup>2</sup>, Lorraine Culley<sup>3</sup>, Tina Goethals<sup>1</sup>, Cathy Herbrand<sup>3</sup>, Nicky Hudson<sup>3</sup>, Sara Lafuente<sup>4</sup>, Vincenzo Pavone<sup>5</sup>, Guido Pennings<sup>1</sup>, Christina Weis<sup>3</sup>

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The motivations of women who provide eggs for the fertility treatment of others have largely been described in binary terms relating to either altruism or financial compensation. This empirical ethics study is part of a larger, multi-phased comparative study (the 'EDNA' study, 2017-2021), which explores egg provision in the UK, Belgium and Spain. We conducted in-depth, face-to-face interviews with 68 egg providers (n=27 in the UK, n= 20 in Spain, n= 21 in Belgium). In addition to asking the women directly about their motives for donation, we used Socratic questioning combined with a specially designed elicitation technique to gather data on the women's moral reasoning and on what they described was 'in it for them' (gains). We will show, (1) how our data on self-oriented (such as reputational benefits, personal growth, rewarding feelings, and social identity-building) versus other-oriented (such as altruistic) motivations and gains confirm that there are a variety of motivations and incentives beyond the altruism-compensation binary, and (2) how our findings can contribute to the normative analysis of the (currently central) role of altruism and the moral acceptability of (partly) self-oriented aspirations in egg donation.

## Developing Etiquette to Support Mentally Disabled Students in Medical School

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Medical career is highly demanding and challenging at the same time. Disabled persons are also welcomed into this field by reservation in India. We hope that this will provide the society medical graduates with empathy which is absolutely necessary for this profession. But the physical, emotional and mental stress which jeopardize the overall well-being of medical students make the disabled students burn-out.

Mental disabilities are easily belittled, under-emphasized and ignored in comparison to physical disability. Disturbances of sleep cycles, regular counseling etc demand extra struggles over the basal line stress of the course which often become a vicious cycle feeling them blocked. Their struggles to go through the daily life in the academic environment go unnoticed which hurt them, may force them eventually to take a drastic step of self-harm or to become anti-social. For these mentally handicapped students, social intervention is equally or more important than medical intervention to attain their goal in medical school. It is the need of the hour to set up "etiquette /reasonable adjustments" for mentally disabled medical students to empower them by removing the barriers according to "libertarian theory of justice". This will make them comfortable to ask for their rights. A team of expert psychiatrists, psychologists, faculties of medical schools, ethicist and of course representatives of mentally disabled medical students and doctors can develop it.

## **Contradiction over Autonomy: Coexistence of Inclusion and Medicalization**

Laura Puumala  
*University of Turku, Finland*

This presentation examines the coexistence of medicalization and inclusion, the two most prominent social paradigms concerning the vast phenomena of human divergence. Arguably, these paradigms are in a profound contradiction with each other. In addition, there is also an inner contradiction in medicalization.

Both paradigms aim at greater individual well-being. The ways of achieving it differ considerably. According to inclusion, autonomy is to be enforced and supported by dismantling structures standing in the way of empowering deviant people. Medicalization promotes well-being by medical interventions. In this process, the person becomes the patient: the sick role is assigned.

Through the sick role two things happen. Firstly, the patient is freed from responsibility over their deviance. Consequently, medicalization indirectly comes to diminish autonomy, contrary to inclusion. Secondly, the patient is required to want and seek medical help for their deviance. Thus, autonomy is diminished concerning their deviance. Yet, patients are supposed to be responsible precisely for their actions concerning their deviance.

How could people be responsible for something, which they are not fully autonomous for? Could the contradictions be reconciled by stating, that medicalization diminishes mainly habeas corpus -autonomy, whereas inclusion promotes primarily Rawlsian socio-political autonomy? Where and how to draw the line between these spheres?

## **The New Harms of Environmental and Health-Related Choices**

Mikko Puumala  
*University of Turku, Finland*

This paper examines New Harms in relation to individual's environmental and health-related choices. New Harms, identified by Judith Lichtenberg (2010), refer to the innocent-seeming and mundane choices like buying a cup of coffee or flying for vacation that cause harm by, say, contributing to catastrophic climate change. This way, New Harms expand morality to areas we usually conceive of as private and non-moral. Modern problems like climate change and global pandemics make it difficult to avoid contributing to harm by everyday choices.

This paper establishes an analogy between environmental and health-related choices, examining their similarities in terms of contributing to New Harms. The paper proceeds in two steps. The first step is to identify the similarities and differences between environmental and health related choices in terms of New Harms to establish the analogy. The second step is to assess the implications of this analogy, with a special focus on environmental and health policy. If every day environmental and health-related choices have moral consequences, could this justify publicly restricting or regulating these choices? For example, a diet can contribute to both environmental and health-related harms by CO<sub>2</sub> emissions and making the individual unhealthy, which encumbers both the climate and health care systems.

## **Moral Distress Among Nurses Providing End-Of-Life Care: Factors, Perceptions and Implications**

Grace Qamar<sup>1</sup>, Daniel Sperling<sup>1</sup>  
*University of Haifa, Israel*

Moral distress (MD) was first defined by the philosopher Andrew Jameton as a painful feeling and/or psychological instability that arises when professionals, including nurses, are aware of morally appropriate professional course of action and required in a particular situation, but cannot act in accordance to it due to institutional, interpersonal, limited power, external limitations or regulatory constraints of a third party. In spite of the fact that research on MD is growing exponentially in the healthcare literature, there exists a conceptual confusion and lack of clarity about the actual meaning of MD. Discussion of multiple theories and definitions of MD makes it difficult to explore MD.

This presentation aims to fill the theoretical gap. It will analyze the current conceptual framework for MD and criticize it while offering a revised theoretical understanding of it. The presentation has three parts. First, three theories of MD will be explored and discussed: Corley's theory of nurse MD; The MD model of Wilkinson; and a feminist empirical bioethics approach by Morley. Second, a critique of these theories will be suggested. In the third and last part of the presentation, a proposal for an integrated model of MD will be offered and evaluated.

## **Challenges Ahead for Ethical Assessment of Clinical Trials after Regulation (UE) 536/2014: Case of Poland**

Agnieszka Rabięga-Przyłęcka  
*University of Lodz, Poland*

EU Regulation 536/2014 introducing a central (may also be referred to as "EU") system of registration of clinical trials for all Member States, provided for the ethical assessment of the planned clinical trial by the ethics committees as a part of the national process of the assessment of the application for authorization to conduct clinical trials. Consequently, it was left to the Member States to specify the rules of functioning a system for ethical assessment of clinical trials of medicinal products. The Member States, including Poland, have been obliged to introduce the national system of ethical assessment that would ensure effective involvement of ethics committees within the timelines for the authorization of that clinical trials as set out in this Regulation (among others in order to avoid the risk of 'presumed consent' without actual assessment by the ethics committee). The defining of these solutions is, for each Member States as well as for Poland, one of the major challenges involved in applying the Regulation. The paper presents the challenges related to the introduction and functioning of the model of ethical assessment of clinical trials in Polish conditions.



## Interoperable Data Sharing in Pediatric Genomics: The Gold Standard for Privacy and Security?

Vasiliki Rahimzadeh, Mildred Cho  
Stanford University, USA

Delivering on the promises of precision medicine to treat the right patient at the right time is a data intensive venture. Bioinformaticists now anticipate that by 2025, the total volume of genomic data will surpass that of the top three current data producers: astronomy, Twitter and YouTube. Many diseases of previously unknown etiology, and for which progress in genomics has been especially significant, present early in life. This substantiates a specific scientific need to access, use and exchange linked genotypic and phenotypic data involving children. Empirical bioethics research supports the conclusion that geno/phenotypic data sharing improves diagnostic precision and accelerates clinical breakthroughs for better health outcomes in children, yet challenges remain when data are exchanged for both research and clinical care purposes. This presentation will share the empirical results of a policy Delphi study to validate 12 policy points that underpin the Key Implications of Data Sharing (KIDS) framework for pediatric genomics. It will also present preliminary findings of a comparative regulation analysis of the 21st Century Cures Act to determine whether the KIDS framework can guide the adoption of uniform standards for data exchange across clinical information systems and jurisdictional borders.

## Data Ethics Principles for Responsible Design and Trustworthy Implementation of Internet of Health Things-Enabled Telehealth Systems

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The COVID-19 public health crisis has accelerated the transformation of healthcare to become increasingly reliant on the provision and use of telehealth services. Internet of Health Things (IoHT) and concomitant enabling technologies have made it possible to shift the delivery of healthcare from traditional clinical settings to remote (home) environments. Although the uptake of IoHT can improve healthcare services and decisions affecting the health of individuals, the "datafication" of health has magnified ethical concerns due to inherent privacy and data protection risks. These concerns stem from the informational asymmetry and uncertainties under which data subjects lack control over their data concerning health, as well as over the "raw data" generated by IoHT, which can be used to derive inferences about them. The presentation maps and assesses the moral requirements that developers, providers and (secondary) data users must satisfy in order to ensure responsible design and trustworthy (ethical and robust) implementation of IoHT-enabled telehealth systems. These requirements entail the deployment of appropriate data governance, data management and corresponding practices (technical, organisational and other measures), which can facilitate the effective implementation of the concepts of privacy and data protection by design and by default in IoHT-enabled telehealth systems.

## The Meaning of the Concept of "Ultimate Morality"

Vojin Rakić  
University of Belgrade, Serbia

The presentation will explain the concept of "Ultimate Morality" (UM). First, it will argue that one of the features of futuristic arguments, as envisioned by UM, is the eventuation of morally enhanced humans. Second, the argument will be advanced that an essential feature of UM is the superseding of the "comprehension-motivation gap". Finally, a set of conceptions underlying UM will be highlighted: Voluntary Moral Bioenhancement, Ultimate Harm, happiness and Involuntary Moral Enhancement.

## Rights Education as an Instrument to Reduce Inequalities and to Include Disabled People in Society: Bioethical and Interdisciplinary Analysis

Eduardo Rala, Jeniffer Dutka  
Sao Paulo University, Brazil

The rehabilitation process of disabled people denotes the emergence of barriers that can limit or hinder their social participation, as well as fruition and exercise of rights. The reduction of these barriers depends on the attitude of changing culture, to facilitate the individual undergoing rehabilitation, support from a multidisciplinary team of health professionals, involving education in rights as part of their process of recognizing oneself as a disabled person. Education in rights is a permanent process, aims at establishing a culture of respect for the fundamental rights and freedoms of human beings, developing their personality and sense of dignity, and promoting the participation of all in a free society. Rights education should focus on raising awareness about the reality of the condition of people with disabilities, their rehabilitation process, identifying the reality of their condition and demonstrating the extent of their sequelae and their physical and psychological impairments, thus aiming at prepare the individual undergoing rehabilitation (and their family) to change attitudes and values, and change situations of conflict and deprivation of rights, thus facilitating the recognition of this individual as a person with a disability in society.



## Public Perception of Genetic Engineering: A Systematic Review of Questionnaire Studies Pre-and Post-CRISPR

Pedro Ramos<sup>1,2</sup>, Maria Almeida<sup>1,2</sup>, Anna Olsson<sup>1,2</sup>

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Since its discovery in 2012, CRISPR-Cas9 represents a promising technology for disease prevention and therapy in humans through genome editing and in animals for food and biotechnology purposes. The longstanding discussion of the ethics of genetic modification remains vivid in the genome editing context, especially regarding human germline genome modification and the impact on the environment and on human and animal health.

We here present a systematic review of studies regarding general public perception of genetic engineering in humans and animals before and after the advent of CRISPR (55 primary publications). A first screening of the data shows three important findings. Firstly, through the Eurobarometers, the European public attitude has been assessed regularly since 1991, whereas for most US studies are post-CRISPR. Secondly, attitude to gene therapy in Europe is changing, with decreasing rejection and increasing optimism in the first decade of the 2000s compared to the 1990s, and this trend continues post-CRISPR. Thirdly, the focus of studies on GM animals shifted after CRISPR, with more focus on the animals per se and their welfare whereas studies pre-CRISPR focused on animals as sources of food and medical products. These results will be expanded in the conference presentation.

## Legal Capacity of Serbia for the Implementation of Living Wills

Mirza Ramusović

Serbia

Serbia is one of the few European countries where there is no specific legislation on the Living Wills. As Serbia is currently in the process of integration to the European Union, constant legislative changes are undertaken in various areas. One of the areas where legislative reform is about to be undertaken is the field of health law. This paper will analyze the legal capacities of Serbian law to implement such concept as Living Wills.

## Lulu and Nana: The First Genetically Edited Babies

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<sup>1</sup>University of Macau, Macau China

<sup>2</sup>University of Coimbra, Portugal

In November 2018, Chinese scientist He Jiankui announced that he had manipulated the genes of several embryos, leading to the birth of the world's first genetically modified babies. The twin girls, Lulu and Nana, are immune to HIV due to the deactivation of the CCR5 gene, performed using the CRISPR-Cas9 technique. They might as well have superior intelligence. In sum, they are enhanced human beings.

The incident raised several issues: technical hazards of the technique, experimentation in human beings, parent's informed consent, human enhancement.

The experiment is also a violation of the precautionary principle, accorded by representatives of several jurisdictions in the gene summits. This principle allows research when its aim is to obtain additional data on the procedure's safety, and also permits somatic gene editing in humans and germinal gene editing in non-humans. It is important to pursue research in this domain. If properly developed, CRISPR-Cas9 can become a useful tool, not only for purely therapeutic interventions, but also for health-related enhancements, such as immunizing a person for certain viruses (similarly to vaccines).

It is still early to know what the future holds for CRISPR-Cas9, but Lulu and Nana gained a place in history, hopefully, not an infamous one.

## Tell the Cancer Pediatric Patient About His or Her Prognosis

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Patient autonomy is enshrined in the Patient Rights Law (2006). Under this law, a clinician must provide the patient with medical information that he/she needs, reasonably, to enable him/her to decide whether to consent to the proposed treatment. In the case of medical information about life-threatening illnesses, such as cancer, the delivery of information to the patient involves many difficulties for both the caregiver and the patient. Communication and delivery of patient information affect the patient-caregiver relationship and are expressed in the quality of life for the patient.

In childhood cancer, the recipients of the information are the parents-guardians and the sick child.

The purpose of the study was to ask the adolescent patient what information he or she would like to receive about his or her illness and treatments.

Methods: We used an interview method with 20 adolescent cancer patients. The interview was conducted by a nurse familiar to the patient during his or her hospitalization.

The study was approved by the ethics committee of the hospital.

The content of the conversation was transcribed by the investigating nurse and we are now in the process of processing the findings.

At the conference, we will be able to present the findings and discuss the results of the study.

## An Ethical Framework to Manage Patient Requests for Medical Marijuana

Michael Redinger, Nicole Fledderman, Parker Crutchfield  
University of Western Michigan, USA

An increasing number of states are legalizing marijuana use for medicinal purposes despite marijuana use remaining criminalized at the federal level and continued Schedule I status by the FDA. Many of those states in which medical marijuana is legal require physician involvement to facilitate patient access. Additionally, physicians may have ethical objections to medical marijuana use or may not believe there is adequate scientific evidence to support its use. The constellation of these factors creates an ethical quandary for physicians when approached by patients for assistance in accessing medical marijuana. This paper provides an ethical framework which provides guidance to physicians in managing these patient requests taking into consideration the above ethically relevant factors.

## Big Data and Artificial Intelligence Implications for Decision-Making in Individual and Public Health Care

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We live in the fourth industrial revolution. It is based on technologies for complete automation of industrial processes that will use cyber-physical systems, Internet of Things and cloud computing. The health industry, in turn, is not on the fringes of this process, including the so-called Internet of things. Everyday objects, such as watches, can already play an important role in monitoring an individual's health conditions. The use of resources available on the Internet to support a professional decision on conduct, or informing stakeholders directly, generates numerous ethical questions, which should not be intended to limit its use, but which need to be addressed, especially as inequalities increase. In this paper, we analyze the moral problems related to the increasing use of mathematical models in the decision making of individual and collective issues and to present possible solutions to deal with them in the daily care and planning of health systems. The results obtained using algorithms, artificial intelligence, machine learning, and deep learning cannot be understood as expressing the best solution, even the most appropriate for a case. We must prevent the naturalistic fallacy and introduce ethical reflection into the decision-making process.

## Spiritual Advocacy in Palliative Care

Francisca Rego, Rui Nunes  
University of Porto, Portugal

In the context of the growing need for quality palliative care worldwide and the evolving multicultural societies, there is a need for a humanizing and individualized care, to address the patient as a "whole". Therefore, suffering in end-of-life patients, namely physical, psychological, social and spiritual, needs to be addressed neutrally, in order to respect the patient's death process, promote patient empowerment and involvement in decision-making.

Spirituality is a multidimensional concept which is closely related to psychological wellbeing and quality of life. It is an essential element in promoting patient dignity and autonomy, given that it influences patients' perception of the illness, of care and death, therefore impacting patients' attitudes and the decision-making process in healthcare. Nevertheless, the existing interventions require further study to determine and address the different needs of specific populations and cultures.

Thus, there is a need for an integration of neutral and non-directive approach of patients' spirituality and preferences in care, across all patients in palliative care. By allowing to neutrally address the spiritual and moral needs of patients, considering their cultural and ethical context, it is possible to protect and promote their moral agency and empowerment, thus respecting the patient's sense of dignity, autonomy and self-determination.

## Dying in Prison: A European Approach to a Dignified End of Life of Prisoners

Angelika Reichstein  
University of East Anglia, UK

Aging in prison is an increasingly important issue in Europe, which is partly due to the increasing life-expectancy of prisoners, but mainly due to tougher sentencing policies. While all prisoners have the right to adequate healthcare, dying prisoners pose additional challenges for prisons when it comes to adequate care.

This paper is based on the first part of a study (funded by a British Academy/ Leverhulme small research grant), investigating dying in prison in order to draft guidelines regarding a dignified end of life of prisoners. Comparing England and Wales, Sweden, Switzerland and Belgium, the study examines the challenges an ageing prison population is posing and the care available to terminally ill prisoners within the prison setting.

Conducting semi-structured interviews with prison governors, this qualitative empirical study is responding to a highly topical, yet under-researched, problem area.

## Research without Ethics: The Crime of the Strasbourg Skull Collection. New Evidences, New Perspectives, New Results

Julien Reitzenstein  
Heinrich-Heine-University Dusseldorf, Germany

A racial war crime as justification for genocide and imperialistic ambitions towards the Caucasus and Himalayas, committed by military medical staff.

August Hirt, an anatomist, murdered 86 people in Natzweiler concentration camp in August 1943. It was believed that his plan was to exhibit their skulls in a museum in Strasbourg in order to demonstrate the inferiority of the Jewish race as propagandized by the Nazis. Fritz Bauer, the attorney general and a leading figure in the prosecution of Nazis, doubted the circumstances of the crime and the motives. He also believed that more perpetrators were involved in the crimes. He died in 1965, subsequently no one was jailed, because many important documents and important evidence was not known to the criminal court. In 2019 Julien Reitzenstein published the scholarly monograph *The SS-Ahnenerbe and the Skull Collection of Strasbourg – Fritz Bauers Last Case*, which exposed further suspects and the true goal of the crime. He retraces the course of the crime on the basis of newly discovered sources showing that the underlying motives leading to the inhumane crimes were even more cynical and cruel than previously known. One motive for this crime was a project of Dr. Bruno Beger, like Hirt an officer in the Waffen-SS. He tried to find evidence about the origin of Nordic People.

## Genetic Selection and Deafness: Between Irreversible Genetic Choice Made by Future Parents and State Interference in Reproductive Life

Carolina Rezende  
Brazil

In 2008 a change in the UK's Human Fertilization and Embryology Act prohibited the selection of "disabled" human embryos when one not known to have "such abnormality" was available. One of the characteristics considered abnormal was genetic deafness. A similar case had already sparked ethical discussion in the United States, when a couple of two deaf women, wishing to have a child in the deaf community, artificially inseminated the genetic material donated by a deaf friend with congenital deafness in the five previous generations. In this case, however, the discussions took place in the ethical aspect, since decision-making came from the private sphere. The case of the United Kingdom, therefore, is paradigmatic because it requires a state positioning, which may open (or close) loopholes for other cases involving embryonic selection. In the Bioethics' field it is extremely important to understand the way other countries face ethical dilemmas and the arguments that are brought out in order to create subsidies for domestic decisions. This paper will discuss some of the arguments raised by those who are not considered hegemonic and empowered in society (in this case, the deaf) based on the constitution of identity based mainly on their own language.

## Should Young Adolescents be Medically Circumcised to Reduce the Incidence of HIV?

Stuart Rennie<sup>1</sup>, Adam Gilbertson<sup>2</sup>, Winnie Luseno<sup>2</sup>  
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<sup>2</sup>Pacific Institute of Research and Evaluation, USA

More than a decade ago, three randomized controlled trials in Africa indicated that voluntary medical male circumcision (VMMC) significantly reduces the risk of males acquiring HIV during heterosexual intercourse. Since then, 23 million males have been circumcised for this purpose, mostly in sub-Saharan Africa. In this presentation, I discuss the ethics of reducing the earliest age for VMMC services down to 10 years to maximize the potential number of HIV infections averted. Many ethically salient considerations are involved: epidemic impact, safety, bodily integrity, informed assent, voluntariness, parental involvement, cultural values, the rise of other new prevention approaches, sexual orientation, and potential stigmatization of those choosing to remain uncircumcised. Examining these complex considerations, I argue that 10-14-year-old adolescents should not be targeted for VMMC initiatives. The discussion is influenced by my experiences as member of the World Health Organization (WHO) VMMC guidance development group, and as investigator in a research team that has conducted empirical research on VMMC implementation in Kenya. Given that some programs are already providing VMMC for this age group, I will also discuss the ethics of discontinuing such efforts, as well as implications of my argument for adolescents between the ages of 15 and 17.

## The Application of the Principle of Autonomy in the Informed Consent Document for the Use of Clinical Data of the Patient

Adriana Ribeiro-Alves  
Universidad de Concepción, Chile

The Informed Consent document has been established as an ethical and legal imperative based on the Universal Declaration on Bioethics and Human Rights (UNESCO, 2005), embodied in the principles contemplated therein.

Of all the principles detailed in a sequence of articles, this proposal contemplates a perspective of application of the Principle of Autonomy, as provided in Article 5 of the Universal Declaration on Bioethics and Human Rights (UNESCO, 2005), specifically in the Informed Consent document when considering the use of patient clinical data.

Even when the subject that deals with the use of data tends to be contemplated in a specific law, the Principle of Autonomy has been strengthened when the subject deals with the use of clinical data of the patient. This force is protected by the principle of purpose, which links the use to what was consented and, therefore, they are legitimized with the rights of access, modification, cancellation and blocking of the use of the patient's clinical data.

From the above, the study presented establishes on the one hand the manifestation of will, from the free exercise that the patient has to demonstrate, duly informed.

## Euthanasia, Assisted Suicide and Psychological Science

Miguel Ricou  
University of Porto, Portugal

The discussion around euthanasia and assisted suicide has been focused, essentially, around two values, the value of life and the respect for autonomy. However, this discussion cannot be restricted to these assumptions. There should be a greater investment in the research about the subject, in particular, the decision-making process and the consistency in hasten death decisions. There is scientific evidence that seems to indicate that wish to die is an unstable phenomenon and may reflect a request for help. In this framework we consider that psychological science should contribute to these issues. However, the role of psychologists in the context of hastening death is not well-defined and has been poorly studied. It is in this context that arise this symposium. A discussion from different point of views can contribute to reflect about the urgency to invest in the study of different issues related to hasten death, in particular, because there are more and more countries discussing hasten death legalization, as is the case of Portugal.

## Just Culture and Medical Law: Professional Ethics, Safety and Accountability

Carolina Rius Alarcó  
Spanish Judiciary, Spain

Just Culture is a new approach to combine safety and proper accountability in high-risk professions. It aims to establish a culture, or framework, to make high-risk professions less stressful and at the same time, to increase customers' (and patients') safety by ensuring that professionals know that they will be held accountable in a fair and just way, eliminating the incentive for self-interested actions that may ultimately be harmful or unadvisable for the final recipient's safety. In the case of Medicine, or Surgery, it aims to create a culture in which medical professionals are no longer driven to avoid actions that are in the patient's best interests for fear of being held liable for acceptable, 'honest' mistakes, should they occur. Also, from a Law and Economics perspective, it strives to change the traditional 'blame' culture for a reporting culture, as a more effective and beneficial policy in healthcare. We will examine the judicial ruling in two criminal cases in Spain relating to doctors and we will study whether a Just Culture approach could have been applied, been relevant, and made a difference in the outcome of those cases.

## Euthanasia and Persons with Dementia: An Ethical Dilemma

Adelheid Rigo<sup>1</sup>, Johan Stuy<sup>2</sup>  
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<sup>2</sup>Free University Brussels (V.U.B.), Belgium

According to the Belgian euthanasia law, people with dementia who want to choose their end of life can only decide for euthanasia in an early phase of dementia, still autonomous, disposing of their full mental capacities. This way, they can lose precious quality lifetime. Are advance directives a possible solution?

Ronald Dworkin differentiates between 'experiential interests' (actual pleasures) and 'critical interests' (values giving life meaning) and builds up an argumentation in favour of advance directives for dementia.

In contrast, Rebecca Dresser focalizes on the 'experiential interests' of a person with dementia, being another person then he was in the past, and concludes that advance directives are useless.

From Agnieszka Jaworska we learn that persons with dementia have, with proper respectful care, much longer than their cognitive capacities, disposition of their values.

By taking the 'ability to value' (Jaworska) in account as an essential part of an autonomous choice, persons with dementia who want to choose for euthanasia can do this in a more advanced phase of the disease and gain a longer quality lifetime. Going one step further, as long as the values of the patient are congruent with his advanced directives, the latter might become reasonable.

## Teaching the Legacy of the Krankenmorde through the Prism on "Biopower"

Michael Robertson, Edwina Light  
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The Krankenmorde (or what has traditionally been termed 'Nazi euthanasia') is the preferred term for an aggregate of crimes perpetrated by the National Socialist (NS) regime against people living with illness and disability. From the point of being virtually sidelined in the United States-v-Karl Brandt et al ('Doctor's Trial') and the subsequent Nuremberg code, the Krankenmorde has been an underdeveloped part of the discourse of the legacy of the NS period for bioethics and there has often been an unfortunate default to facile comparisons with "what the Nazis did". Biopolitics / biopower - a methodology that emerged from the later work of Foucault and later developed by Agamben, Rabinow and others - refers to the government practices of control over the biology of the population as a means of the exercise of coercive power. Biopolitics / biopower interrogates government control over all aspects of life such as reproduction, end of life decisions, reproduction, and concepts of health and illness. In this paper, I will discuss my use of biopolitics/biopower in elaborating the bioethical significance of the Krankenmorde in the setting of teaching mental health ethics to post graduate students through the Sydney Ethics Program, with particular reference to the contemporary challenges of professional ethics and the relationships between professions and the state.

## Quality of Life of the Patients with Ostomy

Antonio Angelo Rocha, Antonio Angelo Rocha Filho,  
Claudia Regina Gomes Rocha, Hadassa Cristina Piedade Inácio  
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Ostomy is an intestinal exteriorization through the abdominal wall for the purpose of treatment, either curative or palliative, of intestinal cancer. However, this procedure can impact on the patients' quality of life, affecting psychological, physical, sexual, social and professional aspects.

**Objective:** to assess the cancer patients' quality of life who have undergone ostomy, mainly approaching the psychological, physical, sexual, social and professional aspects, from the perspective of integrality and longitudinality.

**Methodology:** Cross-sectional, exploratory and descriptive study with a quantitative and qualitative approach, using a sample of 30 patients, obtained by convenience and comprised of the group of ostomized cancer patients in the city of Poços de Caldas (MG) - Brazil. Three validated questionnaires were applied: a sociodemographic and clinical one; the WHOQoL-bref (World Health Organization Quality of Life Short Instrument); and the Stoma-QoL. The inclusion criteria were ostomized patients, diagnosed with intestinal cancer, over 20 years of age, who accepted to reply to the interview and the questionnaire used, through the Informed Consent.

## Bioethical Aspects on Medication Administration Outside Licensed Indications (off-label) in Neonatology

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Medication administration in Neonatology is a legal, scientific and ethical challenge in contemporary clinical practice. The anatomical and physiological characteristics of the newborn, alongside the regulation of their legal rights during clinical trials and their parent's decision-making rights, highlight big differences in comparison with medication administration in adults. Medication administration outside their licensed indications (off-label) in Paediatrics involves the prescribing paediatricians, the nurses that administer them, the pharmacists that manipulate them, the pharmaceutical companies that sell them and the governments that regulate them. Therefore, it demands scientific and legal knowledge from all of them, alongside deep ethical deliberations. Ethics acquire a fundamental role within the objective of analyze medication administration outside licensed indications (off-label) in Neonatology from the basic Bioethical principles: Justice, Autonomy, Beneficence and Non-maleficence. Since ethical deliberation is an essential requirement for the evolution and improvement of clinical practice quality, every stratum involved must go beyond purely scientific facets pursuing the greatest benefit for the newborn.

## Proposal for Hierarchy for Bioethics Consulting

Nathalia Rodríguez Suárez, Paula Prieto Martínez  
*Fundación Santa Fe de Bogotá, Colombia*

Bioethics Consulting is a way to mediate the difficult scenarios that arise in the hospital context. This has generated countless models in order to allow an easy and quick identification of the difficulties that must be intervened and, with it, several proposals to proceed. While there are valuable models for this task, from the experience of the Humanism and Bioethics Service (SH&B) of the University Hospital Fundación Santa Fe de Bogotá has emerged a model of its own, thanks to an experience in bioethics consulting of 6 years.

The proposed model from SH&B emerged from the analysis of a database in which all consultancies since the end of 2013 have been recorded. We conducted a study of the consultancies. With intentional sampling we select the last 50 consultancies. With these 50 interconsultes we carry out a process of axial the psychological-phenomenological descriptive method. The analysis yielded 139 units of content that, discussed at different meetings within the SH&B, allowed to know 3 types of consulting: 1) accompaniment, 2) shared decision-making and 3) bioethical deliberation.

## European Values as Boundaries of the AI Development in the EU

Suncana Roksandic Vidlicka, Doris Skaramuca  
*University of Zagreb, Croatia*

The European Commission adopted on 25 May 2018 a Communication on AI laying down the European approach to AI including preparation for socio-economic changes and ensuring an appropriate ethical and legal framework. EC underlined that the approach should be based on common values, on respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minority. As a consequence, new regulation followed, including the Ethics Guidelines for Trustworthy Artificial Intelligence (April 2019). The Authors are comparing mentioned common values with bioethical principles and critically assessing the EU approach towards the development of AI.



## Redefining Assisted Suicide and Euthanasia to Prevent Discrimination and to Better Align with the Goals of Patient-centered Medicine

Erica Ronning  
Duquesne University, USA

Internationally, the difference between acts of assisted suicide and acts of euthanasia is generally defined by whether the physician prescribes a death-inducing drug that a patient then self-administers, or whether the physician administers the death-inducing drug herself. In those US states where assisted suicide is permitted, this distinction causes accidental discrimination against persons with physical disabilities who cannot self-administer death-inducing drugs. To prevent this discrimination from continuing, I propose that we redefine assisted suicide and euthanasia accordingly: an act should be categorized as physician-assisted suicide or euthanasia depending on whether the patient wants to die or not. If a patient wants to die, and the physician assists the patient in achieving this goal, then this act should be considered physician-assisted suicide, irrespective of whether the physician administers the death-inducing drug or only writes a prescription for it. If, on the other hand, a patient's desires about dying cannot be known, and a physician hastens the patient's death anyway, then this is an act of euthanasia. I furthermore argue that these new definitions should be adopted globally because they are patient-centered definitions, as opposed to physician-centered definitions.

## History of Sweden and German Eugenic's Codes; Biotypological Criteria in Latin Countries

Lucia Rossi  
University of Buenos Aires, Argentina

This presentation intends to research two ideas: We start considering Sweden eugenic code and its influence on social behavior about disability; legal consequences of sterilization and further consequences on demography shape; disability care on institutions and education since it's been created 20' over actuality. Its influence over Nazi eugenic code. Differences in its application over disability subjects and no-desirable social types: direct elimination or experimental studies. Genetic birth control or direct elimination.

The second idea was to present Latin Biotypological criteria based on environment influence of "orientation" to model subjects by education. Applied on European Latin countries and Latin-American countries such as Argentina, are going to be studied considering publications, articles, ortho-biotypological designs on hospital clinic stories and records on education.

We intend to compare both systems, analyzing its presence today in actual codes, health and educational institutions and its actual discourse.

## People with Communication Disabilities: SLTs Speak Up for their Inclusion and Participation

Tiziana Rossetto, Raffaella Citro, Giuseppe Mancini  
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Communication is vital to life; yet communication disorders and difficulties are largely ignored as a disability. The World Health Organization's 'World Report on Disability' estimates that roughly one billion people around the world are living with some form of disability. However, the authors of the report acknowledge that people with communication disabilities may not be included in this estimate, despite the fact that they encounter significant difficulties in their daily lives.

The evidence is clear: communication disability places individuals and their families at greater risk of living in poverty, with children and adults with communication disability generally having poorer academic, vocational, social and health outcomes than those without communication disability.

Therefore, the Speech and Language Therapists' international community has as objectives:

- highlight the lack of visibility and recognition of communication disability
- exchange knowledge about needs and barriers faced by people with communication disability to access and exercise human rights
- strengthen effective transnational cooperation to promote participation in social and cultural life, recreation, and leisure of people with communication disability.

The presentation will show some examples of activities organized by the Speech and Language Therapists' international community in order to achieve these objectives.

## The Need for Universal Protection of the Fundamental Rights of the Human Subject

Elise Roumeau  
University of Clermont Auvergne, France

Either we are dealing with biomedicine in general or with clinical trials in particular, it is a universal protection of the human person that must be sought. The conduct of clinical trials and its consequences require the subject to be protected based on the same principles, regardless of the location. Such rules would make it possible to protect the human subject in developing countries and to avoid the exploitation of their vulnerability. This vulnerability biases the consent of the human subject. National law, incomplete or absent, weakens the protection of human subject. To infringe on the fundamental rights of a human subject in a specific place is to endanger humanity.

Between the framework principles identifiable within the soft law and the rules of criminal law, it is possible to build a pluralistic common law harmonizing the protection of the human subject, while respecting cultural diversity. The adoption of an additional protocol to the Universal Declaration on Bioethics and Human Rights, relating to the protection of the human subject, could then constitute a first step towards a more binding consecration of its fundamental rights.

## Clinical Trials in Developing Countries

Kinga Rozbicka  
University of Warsaw, Poland

Conducting clinical trials in developing countries raises many ethical doubts. The discussion involves arguments whether they bring too much risk of local communities' exploitation or benefit patients who otherwise would have no chance for professional medical treatment. The presentation's aim is to analyze the problem, considering the role of FDA which remains responsible for trials' compliance with ethical standards and including the notion that due to the fact that not all ethical principles are universal for every culture, or they can even be opposite, cooperation between pharmaceutical concerns and local communities in preparing the trial's project is recommended. The above-mentioned ethical rules would be considered with reference to regulations, i.a. DoH and ICH-GCP guidelines, including the standard of care that should be provided for patients on their grounds. The considerations would lead to a conclusion on how to design the trials' frameworks in the most beneficial way both for pharmaceutical concerns and local communities with emphasis put on the ethics committees' supervision over the trials and on the idea to extend it for activities undertaken after the research so as to influence pharmaceutical concerns in their operations to make the products available in the countries involved in the conducted trials.

## Do We Need an Ethical Discourse about Breastfeeding?

Lisa Rubin  
University of Haifa, Israel

The benefits of breastfeeding to infants, children, mothers, and society are well documented and accepted. Despite this, few mothers comply with the public health recommendations to exclusively breastfeed for 6 months. Health service, societal and cultural constraints all contribute to this discrepancy between recommendations and practice, beyond the role of personal choice. The manner in which health care practitioners and public health campaigns promote breastfeeding has the potential to frame women's response to this discrepancy. This has in turn implications for women in how they perceive their roles as mothers and wives or partners. Feelings of inadequacy, failure and blame all too frequently surface in the personal and public discussion on breastfeeding. Are these unavoidable consequences of public health's success in promoting and supporting breastfeeding and the subsequent change in society's attitude? We will consider the ethical implications of this issue, and how it impacts upon the role of the health care practitioners and policy makers in guiding the discourse on this issue which is so key to health.

## The Ethical Dilemmas of Psychotherapy Supervision: Autonomy, Privacy and Power Differentials

Simon Shimshon Rubin<sup>1,2</sup>, Hilla Calderon<sup>2</sup>  
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<sup>2</sup>University of Haifa, Israel

The ethical and professional dimensions of working with therapist personal materials in psychotherapy supervision are considered. To examine whether professional socialization and status influence attitudes, 96 psychologists completed measures of demographic factors; relevance of personal materials in supervision; the ethics of working with personal material; evaluation of supervision behaviors; and also provided narratives of their own experiences in supervision with personal material. Results showed support for view that introduction of therapist personal materials in supervision can lead to significant personal and professional growth. The results also showed limited acknowledgement of the ethical complexity involved with the unfortunate outcome that in both theory and practice, this complexity is not sufficiently taken into account. The presenters conclude with implications of these findings for improvement in the teaching and training of psychotherapists.

## Bioethical Principles in Emergency Nursing Practice: Value Distortion under Heavy Clinical Workload

Alfonso Rubio Navarro<sup>1</sup>, Diego Jose Garcia Capilla<sup>2</sup>,  
Maria Jose Torralba Madrid<sup>2</sup>  
<sup>1</sup>University of Leicester, UK  
<sup>2</sup>University of Murcia, Spain

**Introduction:** Nurses make decisions guided by a professional code of conduct and applied Bioethics that they learn during their training and in clinical practice. Nonetheless, despite the limited training in Bioethics that English nurses have, it is expected that they must understand and adhere to bioethical principles, even under heavy workloads or in emergency situations.

**Objective:** Analyze the application of bioethical principles in emergency nursing practice.

**Methods:** Ethnographic content analysis was used to analyze 1800 hours of observation and 34 semi-structured interviews from nurses working in an emergency department.

**Results:** Interviewed nurses knew the four bioethical principles of Beauchamp and Childress, but their application was distorted by the context in which they had to apply them to. Non-maleficence resulted in tolerance to the suffering of others by not being able to have the appropriate skills or resources, beneficence was limited by defensive practice, autonomy was misunderstood and created the self-care paradox and justice resulted in resource distribution based on subjective factors.

**Discussion:** The concept of bioethical principles is understood by nurses but its application in practice is much more complex. More pre and post-graduate bioethical training is necessary to promote ethical, safe and efficient care under heavy clinical workload.

## Evaluation of the Introduction of Palliative Care Teaching in the Medical Curriculum: University of Campinas, Brazil

Flavio Sá, Carolina Bühl, Daniele Sacardo, Denis Cacique, Jussara Souza  
*University of Campinas, Brazil*

The aging population and the chronic degenerative diseases make the health-disease process extensive and painful. Future doctors need to be trained to work in a comprehensive and holistic care approach. To enable students to consider the need for palliative care, a discipline was instituted in the fourth year of the course of medicine of the University of Campinas, Brazil. The activities included home visits and conversations with patients and family, hospitalized in general wards, emergency unit, oncology ward and neonatal ICU, followed by meetings with teachers for exchange of experiences and reflection. This rotation was evaluated through the application of a semi-structured questionnaire. Communication of bad news, pain management, discussion of prognosis and limits of treatment were considered the areas of major importance. Observation of interactions between doctors and patients, small interdisciplinary groups and bedside teaching were the preferred activities. Students agree that physicians play an important role in providing spiritual support to patients, that palliative care services would improve patient care, and that they would benefit from more palliative care training. They identified that in all medical specialties they will come across patients eligible for such care. This discipline was indispensable to generate reflections about finitude, suffering, frustrations, dignity and quality of life, empathy, iatrogenesis, dysthanasia and orthothanasia.

## Consensus Formation or Striving for an Ethical Position: The World Medical Association (WMA) and its Stand on Physician Assisted Suicide (PAS)

Stephan Sahn  
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<sup>2</sup>Ketteler Hospital, Offenbach, Germany

Medical acts at the end of life have become controversial during the last years. In some countries acts that intent to end patient's life have been liberalized by authorities and legal regulation. Against that WMA holds a strong position against it. In particular, PAS and active euthanasia (AE) are held to be unethical and are to be condemned by the medical profession. As a consequence, two national medical associations decided to leave WMA. In the light of increasing plurality within societies with respect to PAS - in particular in developed countries - WMA has to strive for a justifiable ethical grounding of its position. In this paper WMA's stand on PAS is examined and ethical grounding is analyzed. In the end the position is found to be justified. As a consequence, another ethical question arises: considering increasing plurality within societies a judgment has to be made about what should prevail – consensus formation or establishing a sound ethical position. In this paper it is argued that if human rights are at stake consensus formation is of secondary value. Hence, WMA position is found to be ethically sound.

## Risks and Challenges in Diagnosing

Antonia Sahn  
*Goethe-University Frankfurt, Germany*

Medical diagnosis constitutes a key step in the medical process. It is a condition for effective treatment and can therefore be seen as the beginning of the end of suffering. This hopeful view of the role of diagnosis is challenged by stigmatization, social exclusion or bad prognosis, which can all result from diagnoses. On the one hand, empirical medical data is often linked to discriminating categories which patients find themselves in when they are diagnosed. On the other hand, different moral and cultural ideas balance between the exculpation and exclusion that can follow from being diagnosed with a disease. This way diagnosis opens up questions about how medical data can be understood and what significance diagnosis can have in a social and political context.

In my presentation I will try to use Foucault's analysis of the "exclusion of the mad" to carve out risks that definitions of sickness can produce in the contemporary medical context. In a second step I want to consider his work as an aid for dealing with diagnoses in their social and political dimensions.

## The Teaching of the Biolaw and the Digital Environment: European Project Pro Human Biolaw

José Ramón Salcedo Hernández  
*University of Murcia, Spain*

Science has experienced a biotechnological development barely imagined a few years ago, raising serious ethical doubts and the discipline of bioethics does not get to reach the consensus of the scientific community. In the Bio-Law, it converges Science to reach an advanced and accurate knowledge, Ethics to question the limits and the complexity of realities and Law to offer a just response. This has become more visible by virtue of the digitalization of society and the emergence of technosciences in the personal sphere, which requires greater protection of human rights. The Biolaw faces the challenge of giving an ethical and legal response to the digital era and of training professionals to achieve this purpose. It is necessary to strengthen teaching and research centers in the field of bio-rights and to provide public and private sectors related to health, law, the environment and new technologies to staff with the appropriate experience to offer a legal response to Bioethical problems. That is why an innovative academic offer is necessary; expand the amount of well-trained human resources; boost e-learning; and create an interdisciplinary scientific community large enough to meet social demand. This is the challenge assumed by the European Project Pro Human Biolaw.

## Changing Perspective on Surrogacy: An Upstream Approach

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The heterogeneous regulation across states regarding surrogacy leads commissioning parents to seek cross-border reproductive care, "outsourcing" reproductive labour. Within this system arrangements between parents and surrogates from different countries provide adequate protection neither for the child nor to the gestational carrier. The attempt to register the status of the child born through surrogacy in the state where the practice is prohibited often ends with no legal parent recognition and with the declaration of the state of adoptability. In this context, many concerns regarding surrogacy are still to be faced, since thus far the method of dispute resolution has been a case-law approach, which not always ensures certainty of law and inevitably lengthens the duration of the process of recognizing the child's status. The purpose of this paper is to suggest a self-sufficient approach for the States, thus avoiding the adventitious promotion of "reproductive tourism". By this change of perspective, I will offer a hypothesis of an upstream theorization, questioning if it is possible to look at the surrogate's reproductive capacity as a healthcare service. As an aftermath, it will be possible to build a reproductive labour approach centered on the woman's practice as a surrogate.

## Medicine in the Ghetto: The Lodz Example Ethical and Health Care Services Challenges in the Dark Days of WWII

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The Jewish medical staff in the ghetto was appointed by the Nazi Germans to handle the medical care and sanitation of the Jewish people who were gathered together as herds of "unter menchen" on their way to extermination. These people, who lived a full and fruitful life before the WWII became a part of a herd in which names did not matter, only numbers.

Medical staff was a part of the people. The physicians and nurses and other para-medical staff had to get along with lack of space, lack of equipment and lack of medications. With time, things got worse and worse together with mass murder and no security what is to become next, heroic efforts took place to provide minimal humanitarian help and medical service.

The situation in the ghetto of Lodz will be addressed, together with examples from other ghettos in terms of medical services, nutrition, medical education and even... research. The structure of the Medical and Sanitation Department of the Judenratt will be presented with descriptions of efforts and every day's life in the ghetto of Lodz. This presentation will show the impressive humanistic and moral values of the Jewish medical staff in the ghetto till the end.

## Conscientious Objection in the Nursing Profession: Limitation of Therapeutic Effort and Terminal Sedation

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Diego Garcia-Capilla<sup>1,3</sup>, M<sup>a</sup> José Torralba-Madrid<sup>1</sup>,  
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In the healthcare professions often, moral conflicts appear having to decide whether to perform a professional duty or to safeguard the individual's moral integrity.

Conscientious objection is based on the rejection to participate or cooperate in a technique or procedure for ethical reasons.

Spain's legal framework lacks in many aspects of the definition of this right, where the Nurse is part producer of the therapeutic action.

End-of-life processes, such as the limitation of the therapeutic effort (LTE) or terminal sedation are accompanied by a great decisional weight and therefore a moral burden.

Our objective is to know these ethical conflicts, the legal framework and to identify the casuistry of in situations of LTE and palliative sedation.

We performed a search of bibliography revision including articles published since 2010.

In conclusion, there is the need to reflect on the concept, as well as projecting its inclusion in future legislation. Nursing suffers from a lack of awareness of this right that can be resolved not only by passing regulations, but with the education on ethics and procedures of conflict analysis.

## Bioethics and Alternative Forms of Pregnancy: Surrogacy, Transplantation and the Artificial Womb

Judit Sandor

Central European University, Hungary

For most of human history, it seemed that if a woman did not have a womb, it also meant that she was unable to become a mother. Today, however, even in the lack of a womb, women have different options to have a child. The differences between these solutions are not only biological and medical but also legal and ethical. Over the course of the last couple of years, various promising technologies and experiments have been developed to overcome the biological obstacles to motherhood.

Whenever ethical interpretation appears in relation to the emerging new procedure, it is usually simplistic, exaggerated, and polarized: the technology is either glorified or demonized. For this reason, it is important to see the differences between these procedures clearly as there are ethical aspects that could be foregrounded only in comparison to each other. The presentation is an attempt to provide such ethical comparisons.



## Vincent Lambert: Between the Right to Life and the Right to Die with Dignity

Sofia Santos<sup>1,2</sup>

<sup>1</sup>University of Porto, Portugal

<sup>2</sup>University of Saarland, Germany

Vincent Lambert, a French citizen, became the symbol of a debate that divided his family, civil society (1) and judges.

In 2008, he suffered a severe brain damage due to a motorcycle accident. For years, he received artificial nutrition and hydration through a gastric tube. In 2011, his condition was described as a "minimally conscious" state and, in 2014, as "vegetative" state.

His parents, Catholics, his half-brother and sister submitted a request to the European Court of Human Rights (ECHR), following a decision of the Conseil d'État, in 2014, in favor of the withdrawal of life-sustaining treatment, backing the position of his wife (2), five of his siblings and nephew.

In 2015, the Grand Chamber held, by majority (3), that there would be no violation of Article 2 of the European Convention on Human Rights. On 20th May 2019, the Court rejected the request for interim measures. Days after doctors removed life support, on the 11th of July 2019, Vincent Lambert died.

This debate did not.

This proposal intends to discuss this important thematic based on the arguments of the family, French Courts as well as on the decisions of ECHR.

## New Human Rights in The Age of Neurotechnology

Cleber Santos

Portugalense University, Portugal

The Cambridge Analytica scandal has revealed to the world many facts, and one of them is how much our brain can be manipulated in an electoral process, as provided that our psychological profile be decoded and from there other people can follow the neural pathways of our decision-making process to influence it.

However, it also revealed that the law is not prepared for this kind of event. What happened during the election of President Trump, in the United States, as well as during Brexit process, can be accused of being unethical and is already the study object of neuroethics, but it is not legally a criminal offense.

How to protect the brain and mind, from decoding the psychological profile by external agents interested only in interfering in people's decision-making process to induce them to targeted consumption and voting?

This will be the question we will try to answer.

Our premise is that this influence on decision-making process has been made in all the world through so-called neuromarketing and neuro-persuasion, and that simply prohibiting this is utopia, due to fact that progress cannot be stopped.

Our methodology will be the literature review, based on journalistic, academic and scientific articles.

## Lay Perspectives of Quality of Life in Rheumatoid Arthritis Patients: The Relevance of Autonomy and Psychological Distress

Isabel Santos

University of Porto (ICBAS), Portugal

**Introduction:** In Portugal, epidemiological data on rheumatoid arthritis (RA) patients demonstrated bigger disability and worse quality of life within rheumatic diseases. The aim of this study is to increase the understanding of Quality of Life (QoL) in RA patients and explore the personal features of living with the disease, namely autonomy within the World Health Organization Quality of Life (WHOQOL) framework.

**Methods:** Use of a semi-structured questionnaire which assess socio-demographics variables, functional status and patients' health status with Stanford Health Assessment Questionnaire Disability Index (HAQ-DI). Then, three open questions were made targeting the patients' difficulties and worries in having RA. Descriptive statistics were made for sociodemographic information and health status. Qualitative data was transcribed, analyzed and coded within the WHOQOL and ICF (International Classification of Functioning).

**Results:** Sixty-two RA patients (MAge=56.7; female=83.9%) were interviewed. Most patients lived with RA for a long period of time (M=16.5 years) and presented moderate HAQ-DI scores (M=1.37). Main features of QoL in RA highlight the importance given to physical health, particularly to independence and autonomy.

**Conclusion:** Main results reinforce the weight of feeling independent and autonomous, and support that along with RA's physical symptoms and associated functional limitations, psychological aspects are of great value to these patients' QoL.

## Rehabilitation of Patients with Schizophrenia and Other Mental Disorders: Ethic and Legal Issues

Oren Schwartz, Fadi Daood

Reuth Rehabilitation Hospital, Israel

Patient's cooperation and compliance is hallmark for any rehabilitation process. Schizophrenia affects 1% of the world population, leading to impaired cognition poor judgment and low self-awareness. These characteristics may cause difficulties in goals settings, delays in achieving goals, and poor rehabilitation outcomes.

We have followed the rehabilitation process of 16 schizophrenic patients admitted to our department after severe orthopedic trauma. The main challenges we encountered during hospitalization were imbalanced disease, drug abuse, disregard of contraindications and poor compliance.

These challenges may cause rehabilitation staff to express doubts regarding the admission of schizophrenic patients to rehabilitation departments due to the high mental and physical effort needed in order to treat these patients and their assumed low rehabilitation potential.

We believe that rehabilitation services should be available and accessible to everyone including patient with psychiatric disorders and schizophrenia in particular despite the great challenge they pose. However, in order to achieve best results and protect the patients, the staff, and other patients we believe psychiatrist should be involved in the treatment of these patients, and the treating staff should be trained to cope with these patients. Based on the rehabilitation potential admission criteria and rules should be set.



## Nursing, Artificial Intelligence, Robotics, Roboethics and Law

Giuseppina Seppini, Cristina Razzini, Simonetta Polanski  
*National Associations of Neurosciences Nurses, Italy*

Artificial intelligence and the use of robotics appear to be widespread in different sectors, including the health area, and represent a real industrial revolution, determining profound transformations even in the health system.

There are essentially three areas where AI and robotics are applied: assistance robotics, clinical robotics, rehabilitation robotics, which provide for a division of criminal liability deriving from: use of a defective product; linked to the use of artificial intelligence systems; use of high risk technologies. In terms of legal responsibility, there are a series of open problems, which will determine repercussions on classical categories, such as conduct, causality, author and guilt, offense, influenced by the concept of risk from the so-called unknown technological.

Even within the Nursing, it is possible to affirm that the responsibility ascribed to the use of robotic technologies is interconnected with the concept of care and both are characterized by elements of interchangeability. The "Becoming", an ontological element ascribed to human nature, has become a substantial element of the historicity of the Doctrine and of the concept of accountability. It therefore appears binding also for nurses to develop specialized skills, also in the roboethics and legal fields, with the aim of being able to act by safeguarding and protecting people's health and to face up the current context of scientific and epistemological uncertainty.

## Exploring the Juridical Dimensions of one Health Through Biolaw

Pablo Serra-Palao  
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The interconnectedness between animal health, human health and the state of ecosystems is an increasing focus of attention along several international organizations. The longstanding collaboration between FAO, OIE and WHO, established at 2010 and known as the "Tripartite", confirms the relevance of an interdisciplinary approach to the animal-human-ecosystem interface. In this sense, the 'One Health' approach has been proposed by the Tripartite as an inclusive and holistic line of work capable of recognizing the interdependence between our health and the health of biodiversity and ecosystems. However, the translation into ethical and legal grounds is yet not fully theorized. Underpinning One Health by different ethical frameworks might result in opposite normative claims; and environmental law might not be the best suited branch of law to dialogue with an approach essentially framed in terms of health. Considering this lack of attention, the aim of this paper is twofold. Firstly, we propose an ecological perspective of global bioethics as a desirable ethical framework for One Health. Secondly, we argue that a more holistic theorization of biolaw, not limited merely to biomedicine, might be an appropriate legal framework capable of translating into the legal domain the interdisciplinary work that is being done under "One Health".

## Ethical Precepts in Animal Testing in Brazil and Portugal

Mario Ivo Serinolli  
*University of Porto, Portugal*

**Context:** The ethical precepts regarding animal testing are not a consent yet, and the national literature lacks review researches which broach on that theme.

**Objective:** Identify researches which treat animal experiment, especially focusing on studies about Brazil and Portugal.

**Methodology:** Based on PUBMED/MEDLINE data, the research for studies was done using the strategy "animal[title] AND ethics[title] AND (Brazil OR Portugal)".

**Results:** It is interesting to mark that only 5 studies, considering the database researched, effectively approached ethics in animal research in Brazil and Portugal, outlining a lack of studies developed in both countries regarding the subject (2,7% out of the total published studies on the theme).

**Conclusions:** It must be guaranteed that animal testing take place only in inevitable occasions, according to the utilitarianism of Jeremy Bentham and, on such occasions, the animal rights must be respected and all discomfort must be minimized in as few uses as possible, in order to be accord to the basic principles and current legislation in Brazil and Portugal.

## Bioethics and the Holocaust: Contemporary Lessons on the Body

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In 2013, Tessa Chelouche, Geoffrey Brahmner and Susan Benedict published "Bioethics and the Holocaust", a UNESCO Casebook that features the most comprehensive compilation of the violations of ethical standards in Medicine and Psychology that took place in Germany under the yoke of the Nazis. This book has been available in Spanish since 2018 and it is also part of the syllabus of many courses taught at the University of Buenos Aires. This article intends to highlight the Casebook's value and its influence among Argentine and Latin American students and professionals. The case studies presented by Chelouche and her team not only have retrospective value, given that they essentially review a chapter in Medicine's history, but they also carry prospective value, in so far as they allow for a better understanding of the notion of body and its treatment from an ethical standpoint.

The following project revisits Nazi medicine as portrayed by Chelouche and her team in order to gain a better understanding of recent experimental trends, such as biohacking, uterus transplantation, and human enhancement. Is it fair to posit that the concept of eugenics, pervasive in Nazi Germany, can currently be traced in contemporary science? Is it possible to develop a method that would allow us to tell these atrocities that took place in the past apart from modern bodily interventions?

## Knowledge, Attitude and Practices of Healthcare Professionals in India Towards End-of-Life Care

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**Introduction and Aims:** In India, due to the absence of a legislation on issue of End-of-life healthcare, the Judiciary has laid down guideline for the same. The aim of this study is to find out the Knowledge, Attitude and Practices of healthcare professionals towards End-of-life care.

**Materials and methods:** This is a cross sectional study conducted on intern doctors, resident doctors and professors of internal medicine, surgery and emergency medicine of a tertiary care hospital and private practicing ICU specialist in the city of Vadodara, Gujarat, India. The data is collected through a self-administered questionnaire. Questionnaire used is from a similar type of study conducted on European population. Permission was taken to modify it as per requirement.

**Discussion:** Questionnaire of 280 participants is being evaluated. This study will help find the gaps in the Indian healthcare system with respect to ethics of end-of-life care. The role of the patient in the decision-making process within the ICU is often undermined. My study will provide a guidance to bring about a change in the current paternalistic approach of the doctors.

## Caring without Borders: Transferring a Recovering Child to an Unknown Destiny

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From 2013 to 2018, Galilee Medical Center treated (GMC) approximately 2500 injured Syrians during Syria's Civil War.

Syria was one of the most dangerous places in the world for children during this time.

GMC treated approximately 355 Syrian children during these years. Of these, the Pediatric Intensive Care Unit (PICU) treated the most complicated cases. The injuries varied and their treatment was challenging and accompanied by ethical dilemmas such as the following case study.

Seven-year-old girl injured and treated in GMC suffering from very severe head injury, with ruptured C1-C4 spinal cord. During hospitalization in the PICU, the girl was unconscious, ventilated through a tracheostomy without ability to breathe on her own and paralyzed from the neck down. At the end of the acute critical care treatment, questions about her continued hospitalization were raised.

A girl who it is a resident of Israel with the same health condition would have several options. For a resident of Syria, continued treatment options are very limited.

Who can be involved in the decision-making process? What are the options? Who can decide which option to choose?

These and other questions that the therapeutic team faced will be addressed in the discussion on this fascinating topic.

## Social Inclusion & Positive Rehabilitation of Children with Down Syndrome is Their Basic Human Right: A Thought Paper in the Contextual Environment of Pakistani Society

Saadia Shahzad

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UN- Sustainable Development Goals, in nutshell gave a vision of healthy society that included differently abled & challenged children too. The UN Convention on the Rights of the Child further imposed that no child with disability must be left out from mandatory primary & secondary education on account of their physical or mental challenge. This is being implemented in developed countries for children with Down syndrome (DS) too; but next to none for children with DS in a developing country like Pakistan. A child with DS is denied the right of comprehensive social inclusion, modified inclusive education, & customized employment in country like Pakistan. This turns out to be a failure in developing him into an independent productive member of the society, with high self-esteem. This Thought Paper is an attempt to analyze the existing situation of social inclusion for children with DS in Pakistani society, provision of their basic human rights, identifying the gaps, & influencing factors. There is no comprehensive, systematic, & inclusive model of rehabilitation working in this country that has aimed at the outcome of developing the child into an independent productive person. Based upon the observations & personal experience of researcher, an attempt has been made to develop a holistic model for rehabilitation of DS children employing collaboration of all the stakeholders.

## Feminism and Gender Medicine: A Feminist Analysis of "Gender Medicine"

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The feminist women's health movement battled against paternalistic and oppressive practices within healthcare systems. Gender Medicine (GM) is a new discipline that studies the effect of sex/gender on general health. The international society for gender medicine (IGM) was embraced by the FDA and granted funds by the European Union to formulate policies for medical practice and research.

We conducted a review of IGM publications and policy statements in scientific journals and popular media. We found that while biological differences between men and women are emphasized, the impact of society on women is under-represented. The effect of violence, race, ethnic conflicts, poverty, immigration and discrimination on women's health is seldom recognized. Contrary to feminist practice, GM is practiced by physicians and scientists, neglecting voices of other disciplines and of women themselves.

We show that while GM may promote some aspects of women's health, at the same time it reaffirms conservative positions on sex and gender that can serve to justify discrimination and disregard the impact of society on women's lives and health. An approach that will integrate feminist thinking and practices into medical science, practice and policies will likely result in a deep and beneficiary change in women's health worldwide.

## Bioethics in Ayurveda

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Ayurveda in itself is made up of Ethics. The only form of medicine which carries ethics embedded in it. Charak, Sushruta, Vagbhata these three contributed a whole lot of ethical practices to the world of medicine. From considering every principal based upon nature to bring it up into the light for today's modern world, Ayurveda has been contributing since Ages. Medicine that has animal and plant origin. Beneficial for humans, animal as well as plants, without harming Nature. Ayurveda talks about ethics when it comes to a single person. It has mentioned the qualities of Ideal Doctor and Ideal Patient. What better than this could talk about Ethics? Today's world is struggling with so many environmental crises, some or the other way, Ayurveda can help build a new era taking care of lifestyle and improving it for the betterment of both the planet and the living beings. In the same way, today when we talk about Bioethics and Ayurveda many researches have been presented in order to go hand in hand with different medicines from the world. Where the world is Joining hands in several things, Few Bioethical seeds If planted into Ayurveda could help us develop and bring the old golden touch to a new Era.

## Non-binary Identities: Between Pathology and Questions about the Concept of Self

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Receiving contributions from various disciplines in the field of Health, Neuroscience, Law, Social Sciences, Philosophy, Bioethics, the contest around the concepts of identity, gender and sexuality in the contemporary world constitute a frontier of knowledge and social activism with numerous disagreements, among them, about the pathological condition, deviant, marginal or, alternatively, the normality, diversity and potential for human enhancement related to the experience of people not identified with the gender attributed to birth. This disagreement between gender identity, expression and designation is included in recent nosographic categories such as gender dysphoria in DSM-5 / APA (2013) and the proposed Gender Incongruence category at ICD-11/WHO, expected to be officialized in 2022, which moves it from the chapter on mental and behavioral disorders to another called "Conditions related to sexual health". The presentation offers an initial theoretical development, addressing the multiple enunciation potential of personal identity, with a view to investigating more specifically the relationship between non-binary identities – termed, among other alternatives, as "queer", "fluid", "independent", "expansive", "agender" – and the philosophical approach to a narrative construction of the self.

## An Afrocentric Approach to CRISPR-Cas9: Considering the Ethics of Germline Gene Editing in the South African Context

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Since the advent of gene-based technologies, ethical discourse on whether using these technologies on humans is appropriate has been a divisive issue in bioethics and law in the West. Each significant innovation in gene technology, has presented new and promising possibilities for mankind, but also new risks. From this there has emerged two predominant schools of thought in bioethics: 1) the bioliberals, who focus on the necessity of maximizing the potential of gene technologies for the sake of human welfare; and 2) the bioconservatives, who focus on avoiding potential risks arising from these technologies, both seen and unforeseen, even if this means halting their use entirely. Debates on CRISPR-Cas9 have largely been framed along these lines, and from a primarily Western perspective. In this presentation I argue these issues must be considered differently in South Africa (SA), by being mindful of SA's context. SA faces multiple public health challenges – including the HIV epidemic - which CRISPR-Cas9 may provide a means for responding to. Furthermore, SA law enjoins the state to make access to reproductive and healthcare technologies available. In light of this, when considering the question: "should we allow gene editing?" One might argue that SA cannot afford not to.

## Autonomy of Pregnant Women in Choosing the Mode of Delivery and the Impact in Women Health: A Retrospective Study

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<sup>3</sup>Universidade Federal de Minas Gerais, Brazil

Obstetrics is undergoing transformation, engaged in ensuring the autonomy of pregnant women in decisions related to childbirth, based on scientific information. Although vaginal birth is a physiological event, medicine has evolved to the point where we can achieve safe surgeries with few perioperative concerns in cesarean sections from 39 weeks of gestational age onwards. This opens the perspective on the extent to which we continue to interfere in the pregnant woman's autonomy to choose the mode of delivery when we persuade them to choose vaginal birth.

To compare the perinatal complications of maternal-fetal binomial of primiparous undergoing, 2,507 deliveries between 2017 and 2020 were analyzed, with 1,807 (72.1%) vaginal birth and 700 (27.9%) caesarean sections.

There was no difference in maternal readmission, death, admission to the intensive care unit, Apgar score below seven in the fifth minute, blood transfusion and comorbidities of mothers or newborns between the two types of delivery. Elective caesarean showed less postpartum hemorrhage. It was observed that elective caesarean in primiparous women does not show a greater risk of complications when compared to vaginal delivery. Therefore, the autonomy and the right to choose the mode of delivery can be respect without fear of harming the patient.

## **"Wasteland": The Ethics of Care in the Experience of Female Doctors at the Forefront of the Fight Against Covid-19**

Olgata Silva, Daniele Sacardo  
State University of Campinas, Brazil

Female physicians have worse indicators of Burnout Syndrome and depressive symptoms in comparison to male physicians, and higher rates of sleep disorders and suicide attempts in relation to women of professional age.

Evidence shows that women acting on the front lines of fighting the coronavirus have even higher incidence of anxiety and stress disorders. This qualitative study aims to uncover the defining factors of mental health of women physicians in charge of COVID-19. The data collection was carried out through semi-structured interviews with women physicians working at a university hospital, including professors, contracted physicians and residents.

The key features:

"Wasteland": suffering due to empathy with others' suffering, the overload of the system, impossibility of care, poor patient prognosis;

"Because if we didn't do it. Who would do it?": social accountability towards patients and the pandemic situation.

Women physicians practice the ethic of care, which prioritizes relational aspects and empathy, placing an even greater burden on them. The interferences of the pandemic were not restricted to work, but also affected their personal lives. Greater involvement with patients and the COVID related management, reflected a more significant impact on women's lives. Residents demonstrated more apathy, infectologists showed more social accountability and compassion.

## **Artificial Intelligence in Drug Development to Bring Hope or Chaos?**

Doris Skaramuca<sup>1</sup>, Sunčana Roksanđić<sup>1</sup>  
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Today 350 million people worldwide are affected by around 7000 rare diseases that would estimate take more than \$13 trillion and thousands of years of research to develop potential treatments for. However, with the help of artificial intelligence trained for drug discovery, such treatments are estimated to go from conception to clinical testing in 18 to 24 months with significant price reduction.

Nevertheless, there are limitations that need to be considered concurrently with the advancements. Experts concur that the available data on which machine-learning systems are trained on is deficient and inadequately structured as the millions of medical and patient reports and clinical trials are rarely shared. Clinical testing is another issue. Because the drug candidates developed by AI are yet to be tested on human patients, we are still clueless if those are safe and effective.

Lastly, from a legal perspective, the ownership of such drug candidates remains a stumbling block. AI has drawn more than \$17 billion in investments since 2009 and will likely grow to \$36.8 billion by 2025. It is hard to believe those investments came purely from altruistic reasons.

## **Ethical Aspects of Commercial Surrogacy**

Racheli Silvern, Stefan Cojocar  
Romania

Abstract Surrogacy is an initiated process, whereby intended parents wish to have a child by having an embryo carried in another woman's womb and, after the birth, the baby is given to the intended parents. In Israel, giving birth and motherhood are perceived to great extent as a significant, essential and natural component of female identity and the existence of children is perceived as a vital and central element of couple-hood and family. encourages fertility and family expansion by the Israeli society illustrated by the support of surrogacy and fertility treatments pursuant to the Israeli Embryo Carrying Agreement Law legislated in 1996. The issue raises ethical dilemmas in the global village, this dilemma has become more prominent in the present age, due to the corona virus crisis that entailed cancelling all flights and forcing each country to close its borders to foreign travelers. This study will give a look to comprehend the process of surrogacy according to the economic sociological theory from an Ethical issue.

## **A Change in the Bioethical Worldview over Fourteen Years: Analysis of Current and Future Lithuanian Teachers' Conceptions**

Grita Skujiene, Jurga Turčinavičienė  
Vilnius University, Lithuania

The teachers' beliefs and values have a significant influence on the way of perception of students and must be taken into account in the content and strategies of including Bioethics Education to Natural Science syllabuses. Conceptions of human-nature relation, science impact on faith or vice versa, equality and equity were analyzed as being the emergence from interactions between three poles: scientific knowledge, values and social practices. The major topics analyzed in this study were related to genetics, animal behavior, human biology, environmental problems and religious and quite well represents bioethical view of the world by current and future teachers in Lithuania. The authors twice (2006 and 2020) used a questionnaire prepared jointly within the European project Biohead-Citizen and analyzed bioethical worldview through the perspective over the fourteen years, through the school disciplinary (biology or national language), the teaching level (primary or second level) and the training (in service or preservice). Principal component analysis was used to analyze the data.



## Champagne Needs Lemonade Money: The use of Personal Health Budgets in the NHS

Deowanthi Slade<sup>1</sup>, Chantal Patel<sup>2</sup>

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If a person requires nursing help to enable them to remain at home, then a Personal Health Budget (PHB) can be used.

This allows an individual to use their own health budget to self-determine their social, emotional and physical needs, therefore ensuring they can maximize their quality of life choices.

The budget is set after being assessed by a healthcare professional in discussion with what the individual feels they need.

A care plan is developed which states how the budget should be used. This budget is approved and allocated by the Care Commissioning Group (CCG).

Tensions occur when there is a difference of opinion between the person and the assessor as to what care is required. Tension can also occur if there is a difference of opinion between the assessor who makes clinical based decisions remembering there is limited resources, and the CCG who makes a fiscal decision.

This case study will look at the moral and ethical challenges that may arise when an individual's choices do not match the available funding from the NHS, taking into account the use of limited public funds and how those funds are safeguarded.

## Safely Embracing Culture: The adequacy of the Cultural Safety Paradigm in Canadian and American Indigenous Healthcare

Eric Smith

University of Alberta, Canada

The Canadian and American healthcare systems have long histories of providing inequitable and ineffective care for Indigenous persons. This ineffectiveness is largely attributable to the confluence of socio-political inequities and a lack of understanding of Indigenous culture amongst healthcare providers. In an attempt to rectify this lack of understanding, a group of Māori nurses developed the cultural safety paradigm. Building off of the failures of its predecessors, this paradigm encourages healthcare providers to understand health holistically and socio-historically, as it exists within systems of value (i.e., cultures). The conceptual promise of the paradigm has garnered significant interest in Canadian and American healthcare but has been appropriated in a way that perpetuates the very problems it aims to rectify. Specifically, this appropriation has led to using cultural safety as a means of promoting epistemically oppressive knowledge instead of true holistic cultural understanding. This sort of oppression instils a lack of respect for and injustices against Indigenous people. Although cultural safety is a step towards more equitable healthcare, a new notion of cultural understanding is needed for truly effective care for Indigenous persons.

## Bland: The Omission of the Negative-Act

Tom Smith

De Montfort University, UK

Legal end-of-life arguments are well rehearsed, even if in a state of challenge within jurisdictions. The interested, informed layperson understands autonomy, beneficence, non-maleficence and justice (1) However, in England & Wales at the end-of-life, act and omission principles are fundamentally flawed and therefore an injustice to the dying patient and wider society.

Respectfully, it is contested that the Law Lords in the seminal case of Tony Bland (2) erred when considering act/ omission and that this is as erroneous in 2020 as in 1993, with inherent contradictions. The question is not whether the non-occurrence of 'x' for person 'P' is an act or an omission rather whether an act, omission or negative-act.

Legal recognition of the negative-act; the intentional with forbearance non-action, despite potentially giving rise to the same outcome as omission; removes the conflation with negligence, recognizes intention and diminishes the injustice of labelling an act as an omission, simply to be legally permissible.

The negative-act removes a 'distinction without a difference,' (3) restoring justice to the dying and judicial integrity.

## When Love Hurts: Navigating the Medical and Ethical Terrain in Advanced Dementia Care

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This is a joint presentation bringing the medical and ethics lenses together to review a challenging long term care resident case. This presentation highlights the challenges we confronted when the substitute decision makers (SDMs) were making decisions that were seemingly not in the best medical and moral interests of the resident. Challenges were heightened when the SDMs did not agree between themselves on care and treatment approaches. Of main concern were issues related to dignity and quality of life. This presentation will highlight some of the processes undertaken to ensure the resident's dignity and quality of life were optimized in tandem with attempting to maintain a positive relationship with the SDMs. A narrative approach was used to explore how we, professionals, family members (SDMs), could collaboratively identify how to best serve the client's interests.



## Navigating the Tension Between Individual Liberty and Population Health Benefits in Public Health Nudges

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Libertarian paternalism describes the concept of nudging, which Richard Thaler and Cass Sunstein define as steering individual decision-making while preserving freedom of choice. By framing choices (or altering the environment) to trigger automatic cognitive processes in favor of a desired outcome, the nudge encourages an individual to choose a particular option or behave in a certain way. In medicine, libertarian paternalism has gained widespread attention, specifically regarding interventions designed to promote healthy behaviors. Some scholars argue that nudges appropriately balance autonomy and paternalistic beneficence, while others claim that nudges exploit cognitive weaknesses and, therefore, must be considered coercive. This analysis further explores the ethics of libertarian paternalism in clinical medicine and public health, focusing on several contemporary nudges that use opt-out defaults and incentives. Utilizing the frameworks of Feinberg voluntary choice, Kantian autonomy, and genuine informed consent, this analysis concludes that nudges do in fact infringe on individual liberties. However, despite their limitations, nudges are ethically justified when there is a clear public health benefit to the manipulation of choice.

## Biodiversity Loss as an Intergenerational Problem

Blanca Soro Mateo  
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In the last twenty years, Bioethics and Justice have entered a process of embracing a new global paradigm in temporal terms, overcoming short-termism and departing from a proposal of global responsibility which puts life into forefront. This paradigm—and all what it implies—considers present, past and future generations as part of biodiversity as a whole, projecting the debate around life into the future. Biodiversity loss, as a major global problem for humanity—together with climate change—, needs to be legally addressed considering this temporal paradigm, drawing also from an approach based on vulnerability as a circumstance that must heighten due diligence and which is straighten out with care ethics, involving proportional, precautionary and privileged measures in terms of Justice. This new, comprehensive approach to legally addressing biodiversity loss must be adopted by the development of the European Biodiversity Strategy 2030, which must take into account the ethical implications of protecting life in its temporal dimension, expanding the scope of rights in light of the principle of intergenerational equity.

## Factors Influencing Implementation of Patients Centered Care Among Health Care Professionals: Case of Kahama Town Hospital, Shinyanga Region in Tanzania

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**Background:** Patient Centered Care (PCC) is one of the six attribute of health care quality; the others being safety, timeliness, effectiveness, efficiency and equity. Despite of PCC having great contribution in ensuring health care quality, it is improperly implemented. This study aimed at exploring the factors influencing implementation of PCC among Health Care Professionals at Kahama Town Hospital in Shinyanga Region, Tanzania. The study was conducted between February and May 2019.

**Method:** I used a case study design with qualitative approach. 21 health care professionals (HCP) were recruited to participate in this study; Both FGD and Key Informants Interview data collection techniques were used to collect data from the participants. However, I used content analysis approach to analyze the collected data.

**Findings:** The study reveals that there are two main categories of factors influencing implementation of PCC among HCP at this study setting which is Hospital related (Lack of ethical committee; Organization culture) and HCP related factors (Awareness on PCC, Staff Motivation, Heavy workload and Staff Shortage).

**Conclusion:** Bottlenecking concept of PCC may lead to the risk of impingement on human rights to the vulnerable population (patients) at this study area. Health Facilities should take care of this.

## Digital Wellbeing in Digital Bioethics: Prioritization of Bioethical Issues

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This paper deals with issues related to bioethics, digital ethics, professional medical ethics, and ethics of happiness. An attempt has been made to explain the sense of digital wellbeing as new basic concept for emerging digital Bioethics. After the digital disruption wellbeing has become a term in common internet lingo - "digital good" is even the name of an app. It controls whether we know how to properly manage our smartphone. But what goes beyond the "right" way we are using the phone? Programmers and engineers who produce digital gadgets have no philosophical training. Applied ethics should be a mediator and ambassador in shareholder's digital communication. How can we perceive digital wellbeing through everlasting categories such as Aristotle's? What is perceived as wellness in the digital age? In addressing these questions, it is important to keep in mind that wellbeing has always been linked to moral character. Two generations of digital natives have changed the character building process. A list of bioethical issues on the level of the individual is formulated as risk area for ethical regulations. It is planned to present a survey on ethical prioritization of such risk zone.

### **P300 Wave and the Right Against Self-incrimination: Parallel with the Evidence Obtained by DNA**

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The right against self-incrimination rests on the *nemo tenetur se ipsum accusare* principle, derived from the presumption of innocence. The possibility to extract information from a person's body, based on the theory of passive collaboration, as it happens in DNA collection, means that a person is not self-incriminating but merely admitting an intervention. It is one of the most controversial issues among jurists, who are divided between those who allow some, even minimal, restriction on this right and those who do not allow any restriction.

The present work seeks to answer two essential questions. Firstly, on the assumption of passive collaboration theory, to understand if it is open the possibility of using new ways of obtaining the knowledge only the suspect or accused (eventually) has. On the other hand, given the international censorship of the polygraph, to study the basis for the use of P300 Wave, as a new form of cognitive evocation, under the idea that someone is not actively collaborating, but merely tolerating an intervention in the body, as it is already applied in the US and Spain.

Keywords: *nemo tenetur se ipsum accusare*; presumption of innocence; P300 wave.

### **Person or Merchandise? Protecting Human Dignity and the Environment**

Henrique Souza  
Brazil

When talking about bioethics, many issues could be addressed, especially considering technologies such as CRISPR, gene therapies, artificial womb, artificial intelligence, sensors measuring signs or, simply, allowing following people all over the world and "living robots" ("xenobots").

Each of these technologies brings unimaginable possibilities to society but, at the same time, gives rise to numerous concerns. For example, in a near future, a person will be able to hire a medical service to obtain an embryo with some and specific characteristics. Moreover, this embryo will be developed through an artificial uterus and it will be delivered in a certain date and place. Probably the medical service will give no guarantee of the result intended, but in order to follow the evolution of newborn, the medical service will implant sensors that will allow tracking not only where the newborn is but also all his vital signs related to his location. In this case, the newborn would be considered a person or something similar to a merchandise?

It will be briefly discussed, under the Brazilian legislation, the risk of a person become a thing, losing its dignity as human being. Additionally, this question will be addressed as an environmental issue.

### **Brain Patents in the Legal Landscape**

Tade Matthias Spranger  
University of Bonn, Germany

Appropriate protection of intellectual property has always been considered a fundamental prerequisite for technological and economic progress. Patent law, which plays a significant role in the field of intellectual property rights, also covers, for example, genes, gene sequences and inventions that are not limited to a specific plant variety or animal breed. However, while the corresponding patents have been discussed for decades under the slogan "(no) patents on life", little corresponding discourse in the realm of neuroscience has taken place. Patents granted in this field can cover such diverse areas as medical neurological methods, neurological diagnostic methods, neurological devices, data processing of neurological signals, or computational models of a neurological network/system/cell. The scope of the respective patent protection may not only lead to research obstacles. Rather, massive threats to personal rights, human dignity and health data protection are also conceivable, which could materialize above all if certain BCI applications, brain reading techniques, or in general "the transparent brain" become reality. The presentation will, in particular, describe the conceivable risks for the individual and society. The discourse on brain patents, which is still in earliest stages, is thus to be set in motion and, above all, "brought into patent law".

### **The Future of Human Germline Genome Editing: Legal Aspects**

Julia Stanek  
Andrzej Frycz Modrzewski Krakow University, Poland

Studies involving editing of the human germline genome raise a lot of controversy, including in the context of their possible legal regulations. In this debate, the only agreement is probably that the limits of acceptable interventions in the human genome should be clearly defined. The problem of how we should determine them and whether we need new legal regulations in this area at all remains a matter of debate. By analyzing current state of the regulations in the EU, we can see that it is heading either to completely ban on human germline genome editing, or to try to use existing legal norms for this new research area. However, there is no applicable and legally binding instrument under international law on this issue. In this study, I will firstly focus on analyzing the arguments for and against a worldwide moratorium on human germline genome editing. In the following part, I will present my propositions of the regulation of research and applications relevant to human germline genome editing. The proposed solutions will be tested based on motivational legal theory in terms of their motivational ability.

## Research on Human Germline Editing and The Freedom of Scientific Research: A South African Legal Perspective

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Human gene editing technologies, such as CRISPR-Cas9, show great potential to improve medicine and healthcare but have stirred up international controversy. There is ongoing global discourse on the ethical and legal aspects of research on human germline editing. In this paper I suggest that the global discourse on these issues has thus far largely overlooked a fundamental value – freedom of scientific research. The right to freedom of scientific research is an enumerated constitutional right in South Africa. Moreover, it is recognized as a legal right or freedom in many other jurisdictions as well. I suggest that freedom of scientific research has a telling history and an important role to play in our contemporary societies. Excluding substantial analysis of freedom of scientific research from the global discourse on human germline editing may be legally and ethically expedient but undermines a fundamental value on which modernity was built. I make a case for giving due cognizance to freedom of scientific research in the ongoing global discourse on human germline editing.

## Physician Assisted Suicide: Understanding the Re-instated Framework in Germany and its Rationales: A Template for the International Discourse?

M. Wulf Stratling  
UK

In recognition of ethical and legal principles, alongside medical evidence, suicide, or assisted suicide were never illegal in present-day Germany. Individual doctors and charities gradually began to aid severely suffering patients, who wished to die. Numerous criteria had to be met. These had emerged from a longstanding, transdisciplinary discourse. It recognized complexities and potential risks, alongside a need to have any prevalence transparently monitored and safely administrated. In 2015 an opposing, political campaign resulted in restrictive legislation. It temporarily outlawed assisted suicide by physicians, or other (healthcare) professionals, as a criminal offence, and breach of professional obligations. All elements of this legislation were declared null and void by the German Constitutional Court (2020); duly followed by professional bodies (2021). In consequence, the above, previous status quo has recently been fully re-instated and robustly re-affirmed. The framework will be shown to be systematically coherent and manageable in practice. It derives from a demonstrably logical, basic assumption that suicide, or its assistance, do not constitute sanctionable offences. This provides an ethically more conclusive and pragmatic approach to alternatives, which – reversely – deem these acts as offences, and subsequently generate difficulties and trauma in defining and applying criteria for exemptions from prosecution.

## Nurses' Dignity in Palliative Care: A Focus-Group Investigation

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**Background:** Dignity is a valued concept in the ethical discourse of health disciplines. Nursing's professional dignity, a novel concept related to professional identity, is not clearly defined nor have its characteristics been delineated for its clinical relevance in palliative care and other numerous clinical fields.

**Aim:** This study explored the perceptions of the concept of nursing's professional dignity in palliative care environments.

**Design:** Qualitative data were collected in 12 focus groups with 69 nurses. All participants worked in Italy in either home-care or hospices. Data were analyzed by coding responses with inductive content analysis and developing themes.

**Result:** Five themes were identified: (a) The construct of 'Intrinsic dignity of persons pertaining to respect persons as human beings' was embodied in the essence of palliative care. Several corollary themes underlined this central theme: (b) Professional intra- and inter-relationships and teamwork; (c) Nursing professionalism; (d) Ethical dilemmas, and (e) Relationships with patients and their significant persons.

**Conclusion:** Nurses valued the essence to be respected as persons and respected for their work as paramount and this reflects the coherence of intrinsic dignity and work dignity in palliative care. Nurses perceived their psycho-social relationships with patients and their families as rewarding incentives amidst disputatious interactions with peers and/or other healthcare professionals. Besides, they were also besieged by ethical dilemmas that are inherent in the essence of palliative care.

## Cui bono? Experiments on Animals in the Light of the Activity of Ethical Committees in Poland

Agata Strzdała  
Wrocław Medical University, Poland

Practical implementation of animal research ethical is connected with many dilemmas. Both researchers, who apply to ethical commissions, as well as members of those bodies, who evaluate research proposals, face challenges not only of scientific nature but also legal, philosophical and ethical ones. The Council of Europe in the European Convention for the Protection of Vertebrate Animals used for Experimental and other Scientific Purposes proclaimed the 3Rs rules: Replacement (animals are no longer used for the test if possible), Reduction (fewer animals are used to achieve the defined aim of the test), Refinement (a test should cause less distress to the animals). The presentation examines the most common problems, conflicts of values, and misunderstandings connected with the execution of the 3R rules in Poland. The most common difficulties include conflicting values such as animal welfare vs. liberty and accuracy of research, a proper reception of tests on wild animals, as well as concerns of the retrospective assessment of research projects, and problems with adoption of subject test animals. Additionally, in case of farm animals the issue is sometimes blurry difference between the research procedure and regular veterinary practice (or typical diagnostic test).

## Risk-Benefit Ethical Assessment of Basket and Umbrella Trials

Karolina Strzebońska  
Jagiellonian University, Poland

Precision medicine concerns a new approach in treating patients by tailoring the appropriate therapy to the individual needs and genetic characteristics of a single patient. To test new potential therapeutics faster and more efficiently, new models of conducting clinical trials have emerged. They are called "basket" and "umbrella" clinical trial designs and the number of such trials is rapidly increasing. Still, there is a lack of descriptive and normative ethical analyses of basket and umbrella trials. In my presentation I would focus on the risk and benefit analysis of basket and umbrella trials in precision oncology. First, the description of the risks and potential benefits to study participants and society will be provided. Second, I will assess whether the benefits in basket and umbrella trials outweigh the risks using the Charles Weijer component analysis model. The results of my analysis suggest that the risks may outweigh the potential cognitive benefits and the benefits for participants in these studies.

Careful analysis of risk and benefits in novel research models in the era of precision medicine will enable the proposal of recommendations to increase the benefits for participants and society and reduce risks.

## Stigma Related to Mental Illness and Added Burden of Covid-19 in Older Adults: The Problem and Possible Solutions

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Stigma related to mental illness is a dynamic social process typically characterized by stereotyping, categorizing and discrimination against mental illness. In the last two years, this stigma combined with the COVID-19 pandemic, isolation, fears of contagion, varied political response to the pandemic became a vicious circle affecting the mental health of our elderly patient population. We will discuss the effects of the pandemic on the already existing stigma related to mental illness and the multiple ways it has disrupted the social structures globally. Possible interventions to decrease stigma related to mental illness during a pandemic are numerous. Educational interventions are an effective strategy. Redistribution of healthcare responsibilities and screening protocols to other sectors, for example, integrating mental health into primary care has been one solution studied. Other possible solutions include increasing effective treatment strategies using technology, developing population and community-level platforms to help decrease stigma, amongst others. We will review the literature on current strategies being used in some countries to decrease stigma and what else needs to be done given the added stress of COVID-19 pandemic.

The presenters are from different countries and have considerable experience working in mental health, educating newer generation medical students and resident physicians.

## "Euthanasia" in Nazi-Germany and the Doctor's Responsibility

Johan Stuy<sup>1</sup>, Adelheid Rigo<sup>2</sup>  
<sup>1</sup>Free University Brussels (V.U.B.), Belgium  
<sup>2</sup>Odisee Brussels, Belgium

The Holocaust was the realization of the racial ideology of National Socialism. One pillar of this ideology was the Nazi eugenics and 'euthanasia'. The implementation of Sterilization Laws (1933) for patients with a genetic disorder was the first step in the degradation of the physical integrity of persons. The "euthanasia" program was carried out from 1939 until 1941 on children with physical deformities and on patients with a mental disease. The purpose of the so-called "mercy killing" was the "destruction of life unworthy of life". Although Jews were not eligible for the "Gnadentod", the organization of the "euthanasia" program was used to initiate the systematic extermination of the Jews.

How would I have acted as physician-caregiver under the National Socialist regime? We develop this question considering the judgments on the doctors of several courts starting from the Nuremberg trials. During the process there were doctors who invoked the principle of beneficence. By means of analyzing the philosophy of Karl Jaspers and Hannah Arendt, we point out the moral dilemmas of citizens and doctors under a totalitarian regime bearing in mind the issues of eugenics and euthanasia.

## Legal Discourse about Abortion in Poland: Story about Never Ending Battle?

Marek Suska, Marlena Drapalska-Grochowicz  
University of Silesia, Poland

The Polish "abortion compromise" has been recently destabilized, although the content of the law has not changed. Since 2016, many proposals have been introduced in Parliament to change the current "abortion compromise". These proposals sparked a heated public debate, divided between liberal and conservative circles. In addition, the proposals strictly restricting abortion law have sparked a precedent scale of social protests.

The presentation includes the analysis of the legislative process of acts from the 2016-2018 period and describes how the interpretation of the law in relation to the proposed changes has evolved and thus the access to abortion has been limited - despite the fact that the content of the law has not changed (case study - no access to abortion in legitimate cases). The issue of abortion ideally brings together all the problems of worldview debates in Poland, which are basically based on radical divisions that are incapable of compromising. The presentation aims to show the broader issue - correspondence between ethical values, strong social emotions and legislative process. Authors of presentation try to describe these factors based on an analysis of political discourse in media and the legislative process.



## Different Games? Life and Death Decisions Before and After Birth in Second Trimester of Pregnancy

Janicke Syltern, Lars Ursin, Berge Solberg, Ragnhild Støen  
Norwegian University of Science and Technology, Norway

**Background:** Life-and-death decisions (LDD) during second trimester of pregnancy are "tragic decisions": a choice must be made between death and the birth of a vulnerable baby with uncertain prognosis. Such LDD situations during second trimester include termination-of-pregnancy (ToP) due to fetal anomalies or previable rupture of membranes, birth at limit of viability and placental failure with threatening fetal demise. In LDD situations before birth, the prevailing medico-legal principle is the pregnant woman's autonomy based on bodily rights. The rules of the LDD switches dramatically after birth; the prevailing principle is now "child's best interest", secured by physicians.

**Aim:** To explore how health care personnel (HCP) and parents perceive parental role in second trimester LDD before and after birth.

**Methods:** Normative interviews with different HCP-groups and parents with decision-making experience in second trimester.

**Results:** We found a continuation of ethical concerns in LDD before and after birth. Both HCP and parents prefer HCP to make LDD based on "medical facts", except for ToP due to fetal anomalies, where the decision lays with the mother.

**Conclusion:** HCP should be aware of ethically relevant similitudes of LDD in second trimester, and empower parents, promoting family interest. We propose "postponed-withholding" as alternative to "trial-of-treatment".

## Bioethics: Cognitive Development, Contextual and Relational Mediators

Alejandra Taborda<sup>1</sup>, Agustina Labin<sup>1</sup>  
Universidad Nacional de San Luis, Argentina

Reductionist readings on empirical-statistical results favor explanatory speeches that culminate in signage and exclusion movements. For this reason, it is essential to point out that research results build ways of looking at and understanding reality. In this study, the conclusions read in isolation, for example, account for the negative relationship between low cognitive performance and parental perception of social plans, which would be an erroneous reduction. For this reason, the statistical analyzed performed and the results achieved highlight the importance and the need to carry out thorough studies in order that the interpretation of the results transcends the reductionist explanations. In this way, a contextual evaluation and interpretation is proposed, sustained in the recognition of favoring or risk factors, such as educational, cultural and family history, as well as amplifying readings that imply other diagnostic tests. A comprehensive analysis of meanings is proposed that depends on the history of the examinee and the context of the evaluation. Therefore, the need to create ethical research models that go from the detailed study to the explanatory constructions that put into play the interrelation of contextually located and relationally transversally variables is underlined.

## Faith Stronger Than Death: Treating Jehovah's Witnesses with Blood Products

Luba Tachalov<sup>1</sup>, Anat Engel<sup>1</sup>  
Edith Wolfson Medical Center, Israel

Jehovah's Witnesses, a Christianity messianic organization, believe in several prohibitions, such as refusal to receive blood transfusions or blood products in any form. A prematurely born baby, born at the 26th week of gestation to Jehovah's witness parents, was diagnosed with life-threatening hemoglobin deficiency which required an immediate blood transfusion to save his life.

Despite extensive briefing done by the Neonatal Intensive Care Unit (NICU) team, the worried parents refused blood transfusions. They requested the team to do everything in their power to save their newborn, except providing him with blood and its products. The parents put their loyalty to their personal interests and their religious faith in preference over their child's best interest. According to the Israeli patients' rights law, The issue was brought to the ethics committee chair. A decision was made to provide the baby with blood transfusion based on the following arguments:

(1) A medical emergency treatment; (2) Is expected to improve and save the life of the baby; (3) The working assumption is that the newborn shall receive treatment, life, and ex post facto provide his retroactive consent; (4) According to the law, All three legal parameters were met. Although initially furious, the parents eventually felt tremendous relief once seeing their son, the parents expressed a feeling of a heavy burden was lifted from their shoulders. Unfortunately, after a few days of struggling, he died.

## Review on Development of Chinese Hospital Ethics Committee

Chun-Lian Tang, Li-Xia Wang  
Wuchang Hospital, China

For the last thirty years, hospital ethics committee, first established in the year of 1987, has played an important role in promoting medical research and clinical practice in China. However, for some reasons, there are still some problems that hospital ethics committee is facing with, including the incomplete functioning, being lack of standardized regulations and SOPs, inadequate accreditation and oversight and ineffective safeguards. Therefore, it is suggested to further promote hospital ethics committee construction and development from constructing administration operating systems and improving organizational structure of hospital ethics committee.



## Experience of Moral Case Deliberation as a Regular Clinical Practice in a Teaching Hospital of Taiwan

Hung-Yang Tao<sup>1</sup>, Hui-Ju Lin<sup>2</sup>, Shin-Yun Wang<sup>2</sup>, Yi-Chen Wang<sup>1</sup>, Kwok-Hung Lai<sup>1</sup>, Jong-Khing Huang<sup>1</sup>

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Healthcare providers face ethical dilemmas in their daily work. Unsolved moral problems correlate with quality of care, patient safety, fatigue, burnout, malpractice suit, depression, and suicidal behaviors.

We conduct MCD monthly at 12:00-13:30 since 2006, with multidisciplinary parties and various ranks involved. It includes physicians, nurses, social workers, and other specialties of medical personnel, students, ethics and philosophy teachers, lawyers, district prosecutors, and vice superintendent. Clinical Pragmatism, Hermeneutic method, and Socratic dialogue used interchangeably during the discussion, guided by a facilitator. MCD is very context-bound, instead of using regular medical history format, members must present their real clinical scenario with narrative writing to address the complexity of healthcare and explore deeply inside the dilemmas.

Initially, all the team members had been assigned the job, and attendance was obligatory. We then became aware that MCD is the best way to reflect systematically upon the ethical issue, to solve the dilemmas and ease the moral distress/injury. Finally, more new members and physicians from nearby hospitals join MCD on a voluntary basis. The discussion has been published into 3 books as educational materials. MCD, as a regular clinical practice, not only enhance individual ethical sensitivity, alleviate moral unease, solving the dilemma, but also improve team performance, patient safety, and organizational culture.

## Procreative Non-Maleficence: A South African Human Rights Perspective on Heritable Human Genome Editing

Donrich Thaldar

University of KwaZulu-Natal, South Africa

If the safety and efficacy issues relating to heritable human genome editing can be resolved, how should liberal democratic societies regulate the use of this technology by prospective parents who wish to effect edits to the genomes of their future children? I suggest that recent developments in South African (SA) law can be useful in this regard: The country's apex court established the legal principle that the scope of possible reproductive decisions that parents may make when using new reproductive technologies excludes decisions that will cause legally significant harm to the future child – the principle of procreative non-maleficence. When applied to the topical debate about moral enhancement of future children through genome editing, this principle, considered together with the value of autonomy – a fundamental value common to all liberal democratic societies – would prohibit genome editing that constrains (rather than expands) future children's mental capacity to choose their own values for their own reasons.

## New Taxonomy for Prolonged Disorders of Consciousness May Help with Decisions on Withdrawal of Clinically Assisted Nutrition and Hydration: A Proposed Decision-Making Pathway

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The number of patients surviving severe brain injury is increasing; however, many are left in a prolonged disorder of consciousness (PDOC). PDOC patients can survive for years with appropriate treatment. Unless an advance directive exists, the treating clinicians can authorize withdrawal of clinically assisted nutrition and hydration (CANH) for these patients, based on best interests. The classic terminology used in PDOC range from coma, vegetative state and minimally conscious state. However, a new group of patients with covert cognition has been identified in the last decade, making it necessary to revise the current taxonomy to better reflect our understanding of these conditions. With the introduction of a less ambiguous terminology, the challenges when it comes to withdrawal of CANH of these patients may ease. A decision-making pathway for withdrawing of CANH for PDOC patients, based on a new taxonomy is proposed. These decisions should be based primarily in best interests. Adopting a new classification for the impairments of consciousness would clarify and improve what we think about these patients. Moreover, the development of accurate prognostic predictors would be a major step in the decision-making process as it would influence the beneficent pathway towards the best clinical outcome.

## Students in Health Sciences, Attention Danger!

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Students in health sciences, in danger!

In France in a report of 2018 of the Ministry of Health (Dr. D MARRA: Report on the quality of life of health students), it is noted a real malaise of students in health.

The National Federation of Nursing Students (FNESI) conducted a similar survey in 2017 whose conclusions relate to the state of physical and psychological health of students who deteriorate during their studies in a worrying way. This paper will focus on research on the state of mental health of nursing students.

One hypothesis relates in particular to the discrimination that these students may experience during their training.

According to the literature and in particular a survey of the FNESI, 4 out of 10 ESIs were victims of discrimination within their training institute and or internship. Interactions between students, between teachers and students, between supervisors and interns can be as much a situation of discrimination that can alter the mental health status of nursing students. The well-being of health students and future caregivers is a priority public health issue.

## From Medals to Medical Research: Justice and Stakeholder Duties in Secondary Uses of (Wada) Athlete Data

Rachel Thompson  
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The World Anti-Doping Agency (WADA) holds tissue-derived data and associated other data on over 50,000 athletes in its wholly-owned database (ADAMS). These data have been collected over more than a decade and from a wide range of sources. Data are permanently anonymized. Consent, where it exists, is to anti-doping research.

Athletes in the database are from highly heterogeneous, culturally diverse populations with wide variations in their conception of research and consent, and in their access to the benefits of research. I argue that there may be a duty to contribute to anti-doping research based on the benefits athletes receive from that system, and that such a duty may extend into biomedical research, but that an accompanying duty on researchers to ensure just uses of athlete data, and to comprehend and to minimize culturally-specific harms, exists.

I link these duties to the global nature and importance of sport, WADA and public health research, and outline just uses. WADA's increasing prioritization of public health (and their receipt of international state funding) raises the idea of the global citizen with rights and duties relating to justice at individual and system levels. By examining the ethical challenges involved in research on data from this uniquely diverse non-patient population I draw out previously hidden tensions and make recommendations for research using athlete biological and biographical data that translate to global biomedical research more widely.

## Is the "Electronic Personality" of Artificial Intelligence an Ethical Dilemma? A Reflection on the Legal Consequences of Electronic Personality for Autonomous Robots in the Field of Surgery

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<sup>2</sup>HJB, Switzerland

Artificial Intelligence far exceeds the field of health today. From 1990, robotic surgery became a reality: "we do not even talk about surgery of the future, but surgery of the present" with assisted operations, smart prostheses, personalized treatments thanks to big-data etc. So, the robots become more and more "autonomous". We thus speak of "cognitive" robots that are able to learn from their past experiences and to recalibrate their own algorithms, therefore, their behavior will not be fully predictable, which requires serious ethical reflection. The world of health as the rest of our environment has changed. The repercussions for patients and caregivers are major. The increasing use of robots in surgical medical practice raises many ethical and legal questions, thus presenting certain risks. In 2016 the European Parliament, intervened on the question of the responsibility of the robots. It opens Pandora's box by recognizing the existence of « an Electronic Personality » at robots with rights and duties. If at European level things start to clear up while at the national level the legislator is still about to think in a real fog of scientific and technical uncertainties.

But the creation of a legal personality for robots, is it a good idea? Can it be responsible for his own harmful fact? Does it have sufficient discernment for a fault to be imputed to its? Who should bear the ethical and moral responsibility of robots? Who will pay for damages caused by a robot?

## Teaching on the Ethics of Artificial Intelligence

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Jacqueline Hobbs<sup>1</sup>, Rajiv Tandon<sup>3</sup>

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Artificial Intelligence (AI) is rapidly changing our society and the practice of medicine. AI tools are in daily use in the USA. eg with Electronic Health Records that use machine learning to provide predictive analytics on patient risks, AI interpretation of radiological images, electrocardiogram readings, real time generation of clinical progress notes from recorded clinical encounters, and patient acquired data from activity trackers just to name a few. The explosion of the use of AI has created a lag in skill sets on its use and for questioning the ethical uses of AI, especially in health care. Just as there is a need to rapidly translate research developments into clinical practice there is a need for rapid translation of the ethical implications of AI developments to trainees at all levels of learning. The authors reports on a range of learning programs that have been presented such as continuing education programs for practicing professionals, sessions within existing ethics courses, multidisciplinary global webinars, even courses developed for remote presentation to students. Based on these experiences the authors propose a process for developing an AI Ethics Education Strategy. One of the paradoxical features is a proposal to use AI tools to aid the training.

## Morality and Personality

Danijela Tiosavljević<sup>1</sup>, Pavle Piperac<sup>1</sup>  
University of Belgrade, Serbia

In this presentation morality will be explained as an integral part of the psychological apparatus of human beings, a part of personality. It will be explained as an innermost psychological function and how it relates to other psychological functions. By analyzing disorders of morality, those psychiatric disorders where they manifest themselves will be mentioned as well. At the end, through understanding morality as a psychological function, an attempt will be made to present a new understanding of medical ethics.

## Integrating the Appreciative Dialogue in the Management of the Behavior with Risks for the Health Status

Elena Toader

"Gr. T. Popa" University of Medicine and Pharmacy, Romania

By the magnitude of its negative effects on the general health status, chronic alcohol consumption represents a subject of psychological and social interest, beyond the limits of the strictly scientific medical one. Although medical research, social and economic interventions in the last decades brought about remarkable contributions in the assessment of the dimension of chronic alcohol consumption, systematic comments indicate the focus of healthcare on a dominant system of medical care with curative purpose, leaving little place for interventions for affirmative and appreciative counseling of the individual with unhealthy behavior. Medical practice ascertains that the management of the patient with diseases generated by alcohol does not distinctly entail a component with direct addressability to alcohol consumption, in the circumstances where the issues of chronic alcohol consumption cover an area expanding from the individual to the social space of the community he belongs to. In this paper we propose to approach the integration of appreciative dialogue in primary assistance of chronic alcohol consumption from a double perspective: identification of psychological and social variables in the development of liver disease and exploration of alternative solutions concentrated on positive experience and strategies for management of the behavior with risks for the health status.

## The Identity of Psychology in Spain

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**Background:** In Spain, the development and consolidation of Psychology as a scientific discipline is evident and is reflected in the population, in the press and in the public authorities that are increasingly aware of their beneficial contributions. It's in the health sector where there is a greater and more consolidated labor insertion. However, the functions developed by psychologists are confusing and difficult to define both for the population in general, as well as for other professionals.

**Goals:** Replicate the study carried out in Portugal on the Identity of Psychology in Spanish professionals, in order to reveal if Spanish psychologists share a common and clear position on this issue.

**Methods:** The questionnaire used in the original study, adapted to the Spanish population, was used with three open-ended questions. The data analysis was performed through thematic categorical content analysis.

**Results:** The results obtained are in line with the Portuguese study, a significant number of subcategories were created, indicating the disagreement of the participants in their responses.

**Discussion:** The need to better delineate the objectives of psychological intervention is discussed, in order that the psychology professional builds a solid identity that increases the confidence of the rest of the population in the profession.

## Medical Cannabis: Ethical Issues

Daniel Torres Gonçalves<sup>1</sup>, Ana Gabriela Oliveira<sup>2</sup>

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**Introduction:** There are reports of cannabis use with medical purposes since ancient times. Several benefits have been pointed to medical cannabis, from relieving pain to alleviating spasticity. However, its use has faced several limitations given its association with tolerance and dependence.

Conflicts between such benefits and risks are a topical subject of ethical and legal discussion.

**Methods:** Search of articles in Pubmed with mesh words "Medical Marijuana" and "Ethics" in the last five years, written in English.

**Discussion:** Today, medical indications of cannabis are well known, such as alleviating neuropathic pain, muscle spasticity, anorexia, nausea, and sleeping disorders. Other benefits are relieving the craving by heavy drugs, improving patient general condition and quality of life. Its prescription, when legal, is usually related to the failure of conventional therapies.

However, there is evidence of cannabis use being connected to mental, cardiovascular and other health problems.

Such risks make medical cannabis to constitute, in some instances, a public health hazard. This may present an alarming preponderance in younger age groups.

Prescription of medical cannabis must measure its potential benefits against its likely risks. By doing that, the Hippocratic aphorism of "Do Good or Do No Harm" will be respect.

The evidence-based medicine paradigm should be applied to the field of medical cannabis.

## COVID-19 and Alternative Medicine: The Case of African Traditional Medicine

Mbih Tosam Jerome

The University of Bamenda, Cameroon

Modern scientific medicine occupies a predominant position in the field of medicine in the world today. For this reason, non-Western, indigenous approaches to medicine and healing practices have been constrained to an alternative or complementary position and generally neglected as potential solutions during global health emergencies like the COVID-19. This paper critically examines the role of alternative medicine in the fight against COVID-19. Firstly, I analyze the role of alternative medicine especially in Africa where about 85% of the population depends on traditional and an alternative form of medicine for healthcare. Secondly, I discuss the epistemological and ethical implications of the disregard for or subsidiary role assigned to alternative medicine in the world today. I contend that the disregard for alternative medicine which is motivated more by capitalist and monopolistic interests than by the scientific and prophylactic validity of this form of medicine is epistemologically and ethically objectionable. Some alternative forms of medicine may have solutions to some health problems that have challenged modern scientific or conventional medicine. In the fight against the COVID-19 pandemic, like any other health challenge, it is important to source for, garner, and try-out all possible health solutions that nature has offered mankind.

## Can Autonomy be Recognized Solely by a Legal Assertion of Patients' Rights?

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French law has introduced two tools to convey our wishes to anticipate a state of future incapacity. However, in France there is a lack of knowledge of the role of health care proxy and the ability to draft advance directives (AD). Only 13% write AD and 60% of French people do not know that the End-of-Life Act of 2005 put them in place. The French legislator has strengthened the rights of patients by making the AD binding in 2016. However, the "mille feuille" legislative is not invested by the citizens.

We report researches in human and social sciences conducted in hematology. The medical charts we analyzed highlighted that their content mainly conveys treatment wishes, although patients also use them to pass on personal messages. This emerging role of AD to communicate messages within the family should be valued, even if it is not their original purpose.

The questioning of health care professionals is focused on how to find a balance between the duty of information and not being harmful to the patient by confronting him with an anticipation that can be difficult. In our practice, we have observed that the appropriation of these rights requires a support of the patient in his approach and a self-reflection.

The purpose of these rights is to put the person in a position to make choices for himself, however few people seize these rights. How to promote a societal appropriation of these notions? Are AD the adequate tools for anticipated transmission of its will?

## Bioethics: Knowledge and Attitudes of Medical Students (Clinical Cycle) at Buenos Aires University (Bicentral Study)

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To evaluate 103 students in two Teaching Hospitals (Lanús and San Isidro), 12 questions were asked.

87 / 103 answered them (85%), 71% anonymous and 57 / 87 women.

87 (100%) said they had knowledge of Bioethics and considered it important but 71 / 87 (82%) insufficient.

87 (100%) answered correctly about where to apply such knowledge, giving priority to the solution of health care dilemmas (33/87 – 38%) the patient-doctor relationship (29/87 – 33%), Biomedical Research (11/87 – 13%), etc.

50 / 87 said they know the difference between ethics and morals and 37 / 50 (74%) showed they do and 3 / 87 (4%) know the difference between Bioethics and Medical Deontology.

They know ethical principles (59/87 – 66%) and partially (15/87 – 17%) and nothing (15/87 – 17%), giving priority to autonomy and beneficence. 35 / 87 (40%) suggested better teaching strategies, asking for more articulation between theory and practice.

Conclusion: it is necessary to modify and improve the teaching of Bioethics to future doctors since they themselves recognize their ignorance.

## The Future of Human Reproduction: An Interdisciplinary Work in High School

Norma Trezzi

Italy

The important innovations introduced by assisted reproduction techniques have been repeatedly emphasized in bioethical reflection. But we are still at the beginning. In the future, the ways in which it can be reproduced could change further.

No less important changes could then take place at a social and family level as this could arise from a variable number of parents. Even if the concept of family has undergone several and numerous evolutions in the course of history, it is foreseeable that such a revolution would trigger reactions.

The reproductive technologies that we use today are only a brief step in the path of remodeling and transforming human nature that began tens of thousands of years ago and will continue even after us.

In this work we will confront the future of human reproduction by highlighting the new opportunities that biotechnologies promise to future generations.

The objective of this project, carried out in an interdisciplinary way with the biology, philosophy and law teacher, is to examine the main moral questions that each new reproductive technology raises based on its specific characteristics.

## Integrating UNESCO Bioethics Declaration topics into an Undergraduate Biomedical Engineering Curriculum

Charles Tritt, Jeffery LaMack

Milwaukee School of Engineering (MSOE), USA

The undergraduate biomedical engineering (BME) program at the Milwaukee School of Engineering (MSOE) has a tradition of integrating coverage of ethics into program courses. However, these integrated topics have largely been limited to informed consent and traditional professional engineering ethics topics. Additional bioethics topics were covered in a dedicated bioethics course, typically taken in the students' senior year.

The establishment of an UNESCO Bioethics Unit on our campus has created the desire to integrate a more complete set of modern bioethics topics into the BME curriculum. The challenge is how to find time in an already densely packed curriculum for these topics and to present them to busy engineering students in an effective and engaging way. An additional challenge is the desire to tailor the material covered to those of greatest relevance to engineering, as opposed to more common clinical applications of bioethics.

The approach being taken is to find or develop relevant real and hypothetical case studies that illustrate UNESCO declaration topics and present these in selected BME courses. Case study topics include informed consent, respect for human vulnerability, social responsibility, risk assessment, sharing of benefits and others. Several of these case studies will be shared and discussed.



## Ethics and Nursing in a Wired World

Becky Tsarfati, Daniela Cojocaru  
"Alexandru Ioan Cuza" University of Iasi, Romania

In recent years, healthcare givers and patients have extensively used computerized technologies and digital information. This changed the work environment and skills of nurses to work with both "machines" and humans. Nursing is patient-centered, respecting human dignity and acknowledging patients' needs, they required to promote safe environment and health care, educate, and embrace a health policy for individuals of all ages and communities. Electronic health records are shared through network systems by patients, physicians, nurses, and more. Widespread access to health information requires finding ways for observing patients' confidentiality and privacy by the users. This paper presents four central ethical issues stemming from the use of electronic records ,1) The built-in conflict between nurses' quality care commitment to health system organization and their commitment to maintain patients' respect and privacy. 2) The gap between the one-dimensional reporting of medical and therapeutic information through technological systems 3) The gap between the advantage of technological systems as being easy to operate and use and the risk of leaking confidential medical information, violating patients' privacy. 4) Conflict between nurses' classic professional identity as people who take care of and satisfy patients' needs and the new concept of nursing that advocates patients' privacy, autonomy and dignity while learning new technological skills with all the advantages and disadvantages encompassed in it. This paper ends with writers' point of view about ethical-technological solutions.

## Ethical Dilemmas in Aesthetic Medicine

Yehuda Ullmann  
Rambam Health Care Campus, Israel

Aesthetic medicine is a unique branch of Plastic surgery. We like to call it "reverse medicine" because unlike in regular medical practice, here, the patient tells the physician what bothers him, and the physician is expected to offer the right procedure to help.

In aesthetic procedure, the success is finding the common ground between the patient's expectations, and the physician's judgement, while taking into account the medical history, possible complications, particularly unexpected outcomes, because the patient expects to get 100% success, with no complications. These expectations are almost impossible to be fulfilled, this is one of the main obstacles which this profession faces.

The aesthetic procedures are not covered by the medical insurances, and when money comes to medicine, unique ethical issues may flare-up:

How to choose the patients? Should each patient who enters his clinic have treatment?

What Should be the balance between the patient's requests to the physician's judgment?

What is an "ethical/unethical" advertising?

Should patients suffering from mental disorders be operated on?

What is the role of social media in the popularization of aesthetic procedures?

Should we treat young patients?

These and many other ethical dilemmas will be discussed.

## Shift in the Paradigm for the Protection of the Human Rights of Persons Suffering Mental Illness or Psychosocial Disabilities

Ksenija Turkovic  
Vice-President at the European Court of Human Rights, Croatia

The significance of the pertinent case-law of the European Court of Human Rights (the Court) under the relevant provisions of the Convention, particularly Articles 3, 5 and 8, for the development of the Additional Protocol to Oviedo Convention concerning the protection of human rights and dignity of persons with mental disorder with regards to involuntary placement and involuntary treatment. Special attention will be given to recent Advisory Opinion by the Court and the way to approach incompatibility of the Oviedo Convention (Articles 7 and 26) with relevant contemporary norms as laid down in the Convention on the Rights of Persons with a Disability (CRPD) to which the very notion of imposing treatment without consent is contrary. The paper will also discuss the significance and influence of the shift in the paradigm for the protection of the human rights of persons suffering mental illness or psychosocial disabilities in international law for the further development of the case-law of the Court. The ultimate goal of the paper is to suggest the possible ways to harmoniously interpret European Convention of Human Rights, Oviedo Convention and CRPD and to achieve the greater degree of clarity in defining protective conditions.

## Pregnant Women and Equitable Access to Emergency Medical Treatment

Michael Ulrich  
Boston University, USA

When discussing pregnancy termination, far too often the focus is on women who wish to have an abortion. But the fact is that many women who intend to carry their pregnancy to term suffer medical complications that make such an outcome impossible. In many cases, pregnancy termination is the standard of care. And yet, even these women suffer mistreatment, rejection, and stigma, all while suffering through the trauma of a significant medical ordeal with one of the worst outcomes for a pregnant woman who wants a child. This presentation will focus on the continued deliberate refusal to recognize pregnancy termination as a medical procedure, placing many women's lives and wellbeing at risk and leaving others to suffer exacerbated poor health outcomes. In the U.S. this can be seen by examining the states with most restrictive abortion measures, and the fact that they typically suffer from the worst maternal health outcomes. By shifting the conversation around pregnancy termination to what is often a necessary emergency medical procedure, maternal care will become more of the focus in the ongoing debate over when, where, and why a woman may or may not be able to terminate their pregnancy.



## Teaching Medical Students about Research Ethics and Informed Consent by Considering the Nuremberg Doctor's Trial and the Nuremberg Code

David Urien  
Boston Children's Hospital, Harvard Medical School, USA

US Medical Students often consider Informed Consent as a primarily legal activity. This attitude is supported through the overt and the "hidden" curricula in medical education. I describe an approach that uses the Nuremberg Doctor's Trial and the Nuremberg Code as means of offering medical students an alternative way of considering research ethics and informed consent.

Using transcripts from the Doctor's Trial, students compare activities of National Socialist Medicine with episodes in the history of American Medicine. The US Eugenics movement with forced hospitalization and sterilization of persons purported to be "feeble-minded" are compared with various practices of German Hereditary Disorders Courts. The Tuskegee and Nicaragua STD trials are compared with infectious disease experiments performed at Auschwitz, Dachau and Ravensbrück. LSD administration and nuclear weapons exposure to enlisted personnel in the US Army are compared with cold and high altitude simulation experiments at Dachau.

Students discuss the verdicts offered at the Nuremberg Doctor's Trial and consider what comparable verdicts might be rendered over the US trials and experiments considered. They reflect upon how this trial informed the salient position informed consent takes in the Nuremberg Code, and why subsequent codes of medical ethics have placed it in less prominent position.

## Sticky Lives: The Ethics of Digital and Genetic Postmortality

Lars Ursin  
Norwegian University of Science and Technology, Norway

What could it mean to say that dead persons have interests? In order to have interests, the dead should be susceptible to some kind of harm or disrespect. To protect against frustration of such possible interests, decedents should be granted certain rights. In this paper, I identify four main positions on the question of whether a person can have postmortal interests: (1) dead persons simply have no interests and cannot be harmed or disrespected, (2) to disrespect dead persons means to harm living persons caring for the deceased, (3) persons have interests after their death that frustrate their interests while living, and (4) dead persons have interests and can be harmed as such. Each position has distinct implications for how we should treat the deceased, and possibly protect their interests by legal rights. In this paper, I will discuss the positions and their implications for the narrative ethics of social life and death in the era of digital and genetic postmortality.

## Playing with Fire? Conceptual Issues in Individual Agency and (Lack of) Control in Smoking

Susanne Uusitalo  
University of Turku, Finland

In the quest of gaining more (and better) research on the tobacco control, conceptual rigor is always called for. Public health concerns individuals on a population level, but at the same time, individuals are the target of policies and interventions. They are the basis of public health – no matter how well-researched and well-implemented the practice is, it is the individual who either conforms to it. This provides a strong justification for going into details of the purposes and functions of smoking in these individuals. Unless we understand what smokers look for in their smoking, we have little hope in finding means, tools or practices, to guide the individuals to healthier lives. This empirically gained understanding, however, will fall short unless we also gain a better conceptual understanding of the individual's choices and action. In the presentation I argue for a better understanding of the individual's choices and action as a part of a better policies in increasing and maintaining public health objectives in tobacco control.

## Commercialization of Germ Cell Donation in the Czech Republic

Jakub Valc  
Masaryk University, Czech Republic

The aim of this paper is to point out the legislation and the actual state of germ cell donation in the Czech Republic. My intention will be to introduce the legal conditions under which sperm or egg donation can take place. In this context, I will highlight the problems associated with the unclear definition of the reimbursement that can be provided to donors. I will rely not only on the relevant Directive 2004/23 / EC of the European Parliament and of the Council, but also on national legislation and publicly available offers of individual reproductive clinics. My intention will be to show that the current legislation, in conflict with EU law, creates a wide scope for the application of various marketing practices, including the provision of financial amounts that are in the nature of remuneration. Therefore, it is necessary to consider whether the reimbursement of the costs of donating a given type of human cell should be flat-rate or quantified in some way. At the same time, the risks associated with the current situation (market-based donations) cannot be neglected.

## Preparing the COVID Vaccine Implementation Programme

Johannes (Hans) Van Delden, Rieke Van der Graaf  
University Medical Center Utrecht (UMC), Netherlands

The current COVID pandemic will only stop when there is an effective vaccine. As soon as this has been developed an implementation program will need to bring it to the citizens of the world. It is timely to consider the ethical acceptability of such a Vaccine Implementation Program (VIP). Whereas some might argue that this program must be seen as research that should be in line with international ethical standards, notably regarding informed consent and local ethical review, others might consider it as a public health implementation program that need not adhere to these standards.

**Methods.** We performed a case analysis in light of the 2016 CIOMS International Ethical Guidelines for Health-related Research involving Humans.

**Findings.** We will discuss components that imply that the VIP has a substantial research component. In those cases, it would be prudent to apply ethical norms for research involving humans, such as the CIOMS guidelines.

**Recommendations.** We urge WHO to make any VIP protocol publicly available. Furthermore, in order to improve good ethical practices, it is necessary to engage in international debate regarding the integration of research and public health programs. Procedurally, vaccine implementation programs that combine both prevention and research should involve the wider international ethics community and ensure participation of the target populations in setting the proper conditions for launching such programs.

## Challenges in Seeking the Right, Legal and Ethical Consent for your Study Design

Audrey Van Scharen<sup>1,2</sup>

<sup>1</sup>UZ Brussel, Belgium

<sup>2</sup>Vrije Universiteit Brussel, Belgium

Platform trials, umbrella trials, basket trials, databases and the use big data models... New research designs and medical technology offer challenging possibilities in clinical research. But what with patient autonomy? How can patients still be in control of their participation in clinical research?

Is deferred consent ethically acceptable? Will dynamic consent offer a solution?

This presentation will look into the legal, ethical and practical challenges for a real informed consent.

## Accelerated Marketing Authorization of Medicines: Legal Challenges and Opportunities when Relying on Real World Data

Kaat Van Delm<sup>1,2</sup>

<sup>1</sup>KU Leuven, Belgium

<sup>2</sup>Research Foundation - Flanders (FWO), Belgium

When requesting marketing authorization for a new medicine, various procedures exist in order to speed up the authorization procedure led by the European Medicines Agency. An example thereof is the conditional marketing authorization procedure, as granted for many Covid-19 vaccines by the European Commission. Eligibility for such accelerated procedures is conditional upon the fulfilment of specific requirements. For one of the accelerated procedures in place, specifically the 'adaptive pathways' procedure, the involvement of Real World Evidence is required in order to be eligible for said procedure. After explaining the concepts of Real World Data & Real World Evidence, this presentation discusses why the current legal framework is not adapted to the use of Real World Evidence. In addition, it is set out why the use of Real World Evidence is a relevant criterion for speeding up market access. The main focus of the presentation will be on EU law and the centralized marketing authorization procedure. The presentation will be based on an analysis of the guidance issued by the European Medicines Agency and the goals formulated therein. In addition, EU clinical trial legislation, medical devices legislation and data protection legislation are taken into account.

## Engaging Bioethics Experts in the Biomedical Life Sciences Industry

Pol Vandenbroucke, Diana Pankevich, Edith Eby, Michelle Clausen  
Pfizer Inc., USA

As a healthcare company, Pfizer is committed to thoughtfully navigating ethical issues associated with developing and delivering innovative medicines and vaccines. In 2015, we set out to formalize opportunities for colleagues to engage with, and seek advice from, external bioethics experts. That process led to the creation of Pfizer's Bioethics Advisory Council, whose primary function is to provide independent perspectives on complex bioethical issues at the crossroads of research, medicine, and ethics. To ensure the diversity of these perspectives, the group is comprised of bioethicists from across the globe with unique experiences. The Council informs company decisions with bioethical implications through discussions with colleagues; this ensures that the interests of patients and the public remains at the core of our activities. Topics have included conducting research in vulnerable populations, gene therapies, and patient data. Pfizer colleagues found the discussions, and questions posed by the Council, indispensable in the development of our policies. In the future, we hope to engage with the Council on issues such as artificial intelligence and algorithm development; diversity, equity, and inclusion; and emerging therapeutic platform technologies.

## Canadian Healthcare Providers' Perspectives on using Advance Consent for Medical Assistance in Dying

Caroline Variath<sup>1,3</sup>, Elizabeth Peter<sup>1</sup>, Lisa Cranley<sup>1</sup>, Dianne Godkin<sup>1,2</sup>

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<sup>3</sup>Humber College Institute of Technology & Advanced Learning, Canada

**Background:** In March 2021, amendments to the Canadian medical assistance in dying (MAiD) legislation with the enactment of Bill C-7 allow eligible people who lose decision-making capacity to access MAiD using advance consents. There is minimal data in the literature on perspectives on using eligible patients' advance consent to provide MAiD following the loss of decision-making capacity. This study explored healthcare providers' perspectives on honouring eligible patients' advance consent to MAiD following their loss of decisional capacity.

**Method:** We used a critical qualitative methodology and a feminist ethics theoretical lens. The data includes interviews with 30 healthcare providers from across Canada.

**Results:** Preliminary themes identified include; 1) balancing personal values and professional responsibilities, 2) anticipated benefits of using advance consents, 3) relational influences on decisions, 4) contextual factors that may prevent the enactment of advance consents and 5) anticipated impact of the amendments.

**Discussion:** This is the first in Canada to explore healthcare providers' perspectives on using advance consent to provide MAiD. Although participants believe the new legislation is beneficial, many expressed concerns about its implementation and use. Anticipated challenges include workload increase, establishing unbearable suffering, and family objection. Participants indicated they would honour advance consents on a case-by-case basis.

## Artistic Interpretation of Bioethics Subjects

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<sup>2</sup>European Centre for Bioethics and Quality of Life - UNESCO Chair in Bioethics Italian Unit, Italy

<sup>3</sup>Italian Unit of the UNESCO Chair in Bioethics, Italy

Art represents a free and personal interpretation of other languages that convey significant thoughts.

Bioethical message, if it is translated into the artistic language by students, stimulates the ability to understand, re-elaborate, communicate and interact with others. Not only is it a matter of creativity, but of method as well...

## Children and Youth Bioethics Education

Alessandra Pentone<sup>1,2</sup>

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Strongly inspired by this quote, in 2015 the Youth Bioethics Education Project started its pioneering and challenging path producing two editions of the First Syllabus for Youth Bioethics Education. Based on the UNESCO Chair in Bioethics Cases' methodology, educators and other professional experts realized multiple units containing stories, games, activities, and other pedagogical material tailored for different age groups of children and youngsters. The First Syllabus units are inspired by several 2005 UNESCO Declaration on Bioethics and Human Rights principles. Their purpose is to offer to pupils' knowledge and understanding of ethical values, and to do it in an interesting manner in order to ensure that they will be interested to study them in the classroom and to adopt them in their daily life. Bioethics is a lifestyle. Each society should evaluate the importance to nourish the seed of ethical values that is present in all children.

## Bioethics of PCPNDT Act of India

Srikumar Vasudevan

Government Medical College, India

PCPNDT, an Act of Indian Parliament was enacted to stop female feticides and arrest its consequential societal ills like gender discrimination and other injustices.

The ethical foundation of the Act is rooted in the principles of non-maleficence and justice.

Attempt by pregnant women to know foetal sex results in prosecution whereas female childbirth results in harassment at home.

Only institutions registered under the Act can possess ultrasound machines resulting in onerous paperwork unrelated to prenatal diagnostics thus discouraging non-radiological medical professionals.

PCPNDT prohibits fetal sex identification resulting in non-elimination of fetus with sex linked disorders, but MTP Act allows abortion due to contraceptive failures and foetus with serious abnormalities.

With echocardiography and point of care ultrasonography coming under this act, their use in rural areas is limited. Act has limited the access of ultrasonography to the less privileged rural Indian population worsening the health equity creating ethical and justice concerns.

Act has succeeded in highlighting a grave societal problem but failed to curb female feticide and deliver its non-maleficence aims.

This multifaceted, complex issue has to be re-examined and the law updated with more pragmatism such that ultrasonography is widely available in rural India.

## **Jnetics: 6 years of Genetic Screening within the UK Ashkenazi Jewish Population**

Alegria Vas Mouyal, Nicole Gordon  
*Jnetics UK, UK*

We present a unique model of a British genetic screening programme for individuals with Ashkenazi Jewish ancestry that exemplifies a unique partnership between a publicly-funded healthcare service and a charity. In 6 years, the model has been successfully implemented in hospital and community settings as well as schools and universities. An example of accessibility, providing free screening to all students and disadvantaged individuals, the programme aims to provide a model that can potentially be adopted by other genetically at-risk communities. Overall, 3776 participants were screened by Jnetics between February 2014 and May 2021 and 614 carriers were detected.

Ashkenazi Jews comprise an estimated 95% of the 270,000 British Jews and have a higher prevalence of a number of inherited autosomal recessive conditions compared to the general population. It is estimated that 1 in 5 Ashkenazi Jews are a carrier for at least one of 11 heritable conditions. Most of these conditions are fatal in early childhood, are associated with significant morbidity and have a large emotional and psychological impact on families.

A relatively substantial proportion (32%) of all carriers identified did not have 4 Ashkenazi Jewish grandparents. This shows that it is important for individuals with some Ashkenazi heritage to be screened for 'Ashkenazi' Jewish genetic disorders even if they only have partial Ashkenazi ancestry. 15% of carriers identified knew they had a family history of that condition. This shows that known family history is not a particularly good predictor of carrier status. It is therefore very important that people get screened for these disorders even if they have no known family history of them.

In October 2021, Jnetics expanded the panel of disorders in their screening programme. The test now covers 47 Jewish genetic disorders, including disorders relevant to Sephardi and Mizrahi population. We therefore expect to see an increase in the total number of carriers detected through Jnetics screening programmes.

## **Compulsory Treatment of Pregnant Women Suffering from an Alcohol or Drugs Dependency**

Céline Verstraete  
*University of Antwerp, Belgium*

In February 2020, a legislative proposal was submitted in Belgium in order to enable the compulsory treatment of pregnant women suffering from an alcohol or drugs dependency. Given the major legal and ethical implications, it is expected that this proposal will give rise to a fierce debate. In this presentation, I will discuss the scope of the fundamental right to private life and of the associated obstacles in exerting coercion on a person in a healthcare context. Subsequently, I will address the legal and ethical questions that are raised with regard to the compulsory treatment of pregnant women. This will shed some light on the discussion about the acceptability of using a strategy of coercion, rather than one of persuasion, in this context. More specifically, I will examine whether and, if so, to what extent, it is justified to restrict or infringe upon the right to self-determination of pregnant women in order to prevent irreparable damage to the child.

## **Patient Communication in the Digital Era: Where to Draw the Line**

Roopa Verghese<sup>1</sup>, Jewel Jacob<sup>2</sup>  
<sup>1</sup>*The Center for Bioethics, India*  
<sup>2</sup>*Muthoot Healthcare, India*

The art and science of care surrounding the traditional face-to-face patient/doctor interaction will be forever changed as all aspects of communication, interaction, and information flow will become mediated by electronic tools. Digital communication will accelerate health and healthcare evolution because it diminishes the concepts of time and place. Healthcare will continue to grow and be transformed in the digital environment. Therefore, thinking about health communication in this broader context is essential if the goal of individual and population wellbeing is to be achieved. Population/community centric delivery systems can help to achieve this goal by integrating their "medical care" e-health networks with home-based monitoring systems.

The infusion of technology may make it possible, or even mandatory, that future clinicians focus more on the art of care given that the technical side of medicine will increasingly be handled by digital team. The aim to share knowledge and exchange thoughts and opinions. use these tools to diagnose, treat, and support the patient-centered needs of each individual, as well as the overall socially balanced needs of the community, will become a paramount goal of all high achieving clinicians and practice organizations worldwide. Certainly, Digital Health Communication has a crucial role in today's online world, but the balance is to be maintained by us.

## **Legal Mechanisms Available to Pharmaceutical Companies to Avoid their Civil Liability for Covid-19 Vaccination**

Silvia Vilar González  
*Universitat Jaume I, Spain*

The pharmaceutical industry has worked with haste to develop efficient vaccines to fight the Covid-19 pandemic that has placed the international community in the face of an unprecedented health crisis. However, many experts warn about the risks of approving vaccines in a hurry, without having adequately verified their safety or efficacy thresholds in humans.

In this context, various pharmaceutical companies have conducted negotiations with the European Union and other individual countries, to determine who would take over the indemnities that could derive from the adverse secondary effects derived from the administration of said vaccines in the users.

Thus, if the potential vaccines that are being administered fail in the European Union, or do not work as expected, the European Commission has reached an agreement with the different manufacturers, within the framework of its vaccine strategy, in basis on which, although the responsibility should be assumed by the respective laboratories, it would be the Member States who, in practice, would compensate for certain responsibilities contracted under specific and strict conditions. Other countries have legal mechanisms that directly allow the pharmaceutical industry to exempt itself from its responsibility in these contexts, such as the US PREP Act, which we will see.

## Quality of Life, Well-Being and Values: Subjectivist and Objectivist Approaches

Stelios Virvidakis  
National and Kapodistrian University of Athens (NKUA), Greece

The issue of the quality of life has become the topic of more or less technical discussions concerning the efficient satisfaction of basic needs and the promotion of the well-being of members of contemporary societies. Social scientists, professionals in various areas, public officials and ordinary citizens engage in such discussions, drawing on a wide range of pre-theoretical beliefs and intuitions, as well as on scientific and philosophical theories, and expressing ideological commitments which provide normative guidance. In this paper, I undertake a philosophical investigation of an array of concepts, related to the very notion of the quality of life, such as well-being, happiness and the meaning of life, with an aim to analyzing their content and to assessing their importance for dealing with problems in bioethics. I try to highlight the anthropological presuppositions and the framework of values involved in the construal of these concepts. I shall argue that they cannot be properly interpreted unless one combines subjectivist and objectivist approaches at different levels, thus adopting a complex conception of the quality of life, to be employed in bioethical reflection and eventually in practical decision making.

## Bioethical Aspects in the Fast-paced Biotechnologies and Innovations: Rights, Duties and Responsibilities

Mariia Volik, Tetiana Ashcheulova  
Kharkiv National Medical University, Ukraine

Usage of modern technology leads to achievement new opportunities in science dealing with a human and a world in general. At the same time, this new stage in the humanity's evolution raises a number of new ethical questions called NEST-ethics. The prefix NEST stands for New and Emerging Science and Technology. Do we have the rights to use the NEST products with the long-term unknown consequences, which might be difficult to control? Optimists suggest that NEST will solve problems of global warming, clean water and public health. Pessimists are afraid of the loss of privacy and safety, unforeseen environmental and health risks. Thus, ethics of responsibility is a current question based on the 3 main "P" principles: profit, people and planet. Do using microchips mean just human's identification or total control and manipulation? Does GMO-products have negative impact on target organs? Is it safety to provide personalized medicine using GNA code? The most controversial questions discussed nowadays are about Genetic engineering and its impact on biological species. These questions require special attention because the results of using technologies can be unpredictable and carry uncertain risks for society.

## Promoting Patient Safety: Legal and Ethical Dilemmas

Vlayko Vodenicharov<sup>1</sup>, Konstantin Shterbakov<sup>2</sup>, Sashka Popova<sup>1</sup>  
<sup>1</sup>Medical University - Sofia, Bulgaria  
<sup>2</sup>Sofia University "St. Kliment Ohridski", Bulgaria

The main objective of the study is to assess the magnitude of patient safety culture and the need to create the necessary legal environment and put mechanisms in place in order to enhance access to safe and quality healthcare for patients. The findings of our study showed that in recent years, there has been growing awareness of the number of errors, incidents and near-misses that happen in healthcare and the effect on patients.

Promoting patient safety highly depends on achieving a culture of medical practitioners for understanding how a cultural context shapes perception about why errors happen and how practitioners learn to think about and deal with them. The study justifies the need for training of medical students and medical specialists for identifying, assessing, analyzing and managing all potential risks that directly or indirectly affect patient safety in the conduct of medical activities.

Arguments are given about the need of continually updating teaching curricula and teaching practice in the modules on organizational behavior and culture, risk management standards, patients' rights, guidelines for good medical practice.

## Rethinking Vulnerability in the Presence of Disability: Challenges or New Possibilities?

Martina Vuk  
University of Fribourg, Switzerland

The attribute vulnerable in the history of medical health care services has been a mark of ill, sick, disabled. The autonomous, on the other hand signify the self-dependent, invulnerable, healthy individuals. Being assigned with the attribute of vulnerable, not only diminishes a person's right to autonomy, independent living, freedom, rights and participation in society, but perpetuates oppressive conceptual misrepresentations and socio-cultural behaviors towards disabled.

People with disability historically have been assigned with the adjective vulnerable individuals, and they remain classified as vulnerable within contemporary International UN documents (cf. United Nations Universal Declaration on Bioethics and Human Rights; CIOMS 2010; IBC, 2013). In this presentation, employing the comparative and critical method, I intend to challenge the mainstream thinking on vulnerability - not merely as a category of disabled people, but as specific condition humana. In such regard it is my assumption that the term more than vulnerable referring disabled, instead of vulnerable being mark of only disabled, is anthropologically more adequate and comprehensive way of living humanness, as it not only points upon vulnerability as human condition of all but avoids anthropological gap imposing distinction between vulnerable and non-vulnerable individuals.



## **The Doctor as a Rubber Stamp: The Doctor's Ethical Dilemmas in Signing Medical Certificates**

Yossef Walfisch

*The Israeli Medical Association Ethics Bureau, Israel*

Signing a variety of medical certificates for patients is one of the most frustrating and time-consuming tasks with which doctors deal.

There are many different certifications that physicians are requested to sign, including "sick notes", qualification certificates, insurance forms, and government certifications.

Many doctors question the necessity and responsibility of the doctors signing these forms in accordance with their professional and ethical values.

Signing certificates (or choosing not to) raises the potential to violate many principles of medical ethics, from patient autonomy to the dilemma between the patient's needs and requests and the doctor's professional truth, to the principle of justice, which may be compromised by signing permits that may financially harm the society or cause discrimination.

Following a number of complaints surrounding unreasonable approvals, the Israeli Medical Association Ethics Bureau formulated a position paper providing ethical tools to aid the physician in deciding which approvals to sign and which to avoid signing.

As a rule, signing a certificate should be a professional matter based on medical knowledge and judgment. A physician should not sign certificates whose entire purpose is bureaucracy or cover up.

A physician is expected to utilize trust and communication skills and to describe the patient's true health condition in any certificate required.

Policymakers must strive to reduce unnecessary bureaucracy and prevent issuing of unethical certificates, which potentially lead to both violation of medical ethics as well as to doctor burnout.

## **Orchestration of a "Good" Death: Different Perspectives on Dying in Germany**

Andreas Walker

*Ludwig Maximilians University Munich, Germany*

Since September 2017, the Institute of Sociology, together with the Chair of Moral Theology of the Ludwig-Maximilians-University Munich, has carried out a research project that aims at the various perspectives and normative patterns of "good" dying. Currently we have visited five hospices and two palliative care units in Germany, participated in team meetings and conducted almost 150 interviews with patients, relatives, nursing staff, physicians, therapists and pastors.

Basic questions of our research are:

How are a "good" terminal care and a "good" death orchestrated?

What is for whom and when a "good" dying?

First results are:

Whether a death is "good" or "bad" is the result of an active process in which the dying persons are as involved as the social environment. An individualization of a "good" dying takes place before the background of rationalization (of disease), bureaucratization (of necessary infrastructures) and routinization (of nursing practices). The individualized patterns of death and the general institutionalizations that make them possible are mutually dependent and mutually complementary. But not always everything is optimal. Sometimes dying is boring and banal, sometimes patients want to live longer, but the single day is already too long. Between patients' hope and despair the institutions try to find a way to guarantee at least a good enough death.

On the conference we would like to present these and other aspects of our research.

## **Sustainable Knowledge for All in the 21 Century: A Biblical Epigenetic and Linguistic Map That Connects Speech Behavior to an Invisible Scale of Nature**

Liora Weinbach<sup>1</sup>, Yehuda Kahane<sup>1</sup>, Ernesto Korenman<sup>1</sup>

*Synchro-Talk Ltd, Israel*

Multidisciplinary research among speakers of twelve world languages has exposed universal aspects in the Human discourse. Cooperation with Dr Ernesto Korenman has led to mapping various stable patterns of discourse and their inter-relation to the activity of centers of conscious and unconscious processing in the brain. This conception was upheld by means of MRI and by Isotopic brain mapping by Prof Tzila Zwass. The above discoveries facilitated the development of Switch My Mind (SMM) Methodology, a practical methodology to self-upgrading and maximizing of Human intelligence and Discourse.

The interdisciplinary findings on which SMM is based have been compared and associated to relevant passages in the original biblical text. This linguistic research has revealed within the Bible a 'Model of Epigenetic Layers that activates stats of mind and are reflected in a scale of speech behavior'. The biblical model of Epigenetics connects Sciences with Heritages like the New Testament, the Koran, Buddhistic and the I Ching. Such universality emphasizes the tremendous potential contribution of SMM methodology as a tool for the unification of peoples, languages, sciences and national heritages.

On the basis of the Biblical Epigenetic Map, a new Technology for mobile phones has been developed: the "Synchro -Talk & Tech" technology in cooperation with Dr Ernesto Korenman and Prof Yehuda Kahane, for the global entrainment of Humane Intelligence based interactions.

1. The goal of this development is to make the SMM method accessible to all interested without the need of intermediaries/facilitators and with the intention of realizing a social vision of equal opportunities for all without discriminations.

2. The technology teaches and trains the principles of SMM method and facilitates its practical application to resolve domestic situations of unrest, stress, mood-swings, depression, anxiety, conflict resolution, decision-making, etc. online, anytime and anywhere.

3. In addition, the technology permits the evaluation of the effectivity of SMM entrainment through an innovative voice feedback technology based on the monitoring & analysis of short, (0.25sec), voice samples to provides instant individual feedback and general progress quantitative assessment. The presentation will introduce: A Multidisciplinary, multicultural, educational Epigenetic Map graded for all ages and populations.

A new meta-cognitive language for self-upgrading.

Synchro-Talk Technology; A new voice-based technology for individual and population entrainment and assessment.

Preliminary experimental findings regarding the recent implementation of SMM and Synchro-Talk among teachers, parents and children in areas of high degree of conflict.

## Lessons from Germany: The Case of Monuments that Honor the American Doctor J. Marion Sims

Andrew Weinstein  
*Fashion Institute of Technology, USA*

My paper examines American attitudes toward nineteenth-century American medical pioneer J. Marion Sims, the "father of modern gynecology" who conducted research on enslaved women, without anesthesia. Responses today, I demonstrate, developed in reaction against American Neo-Nazi ideology, in imitation of present-day German responses to Nazi history.

Recent American Neo-Nazi violence, promoting memory of the Confederacy (the slave-owning South), mobilized Democrats and Republicans to remove Confederate monuments. In this context, news about a controversial Sims monument in South Carolina directed attention of New Yorkers to their own Sims monument. Some demanded its removal. Others argued removal would erase history and advocated adding a plaque or another sculpture. Even Harriet Washington, author of the magisterial "Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present," favored preservation. Then Washington visited Germany, whose zero-tolerance position about honoring anyone affiliated with the Nazis influenced her and subsequently contributed decisively to the American response. The statue was removed.

The Nazi Doctors Trial prompted American jurists in 1947 to write the Nuremberg Code, which established bioethics. Today, Nazi history and its Neo-Nazi legacy are principle forces that shape ethical responses to memorialization of historical medical atrocity in the USA.

## Stakeholders Involvement in Developing an Organizational Code of Ethics in a Hospital Network

Yossi Weiss, Dvora Pikkil, Iris Sellam  
*Assuta Medical Center, Israel*

Writing and implementing a uniform organizational code of ethics for hospital employees and stakeholders is a complex and challenging process. The code addresses possible ethical issues and regulates the relationship between the organization and its stakeholders.

Assuta Medical Centers (AMC) has created an organizational code of ethics in a process of three steps.

First, a wide steering committee was established in order have adequate representation for all levels of management and for various sectors of hospital staff.

Second, conversations with focus groups were held at each of medical centers

Finally, key stakeholders were identified through a comprehensive analysis of the organization's activities and key interfaces. The selected stakeholders represented employees, patients, physicians, HMO'S, insurers companies, pharmaceutical and equipment providers, health tourism agents, regulators and ethics professionals. Insights gained in meetings with these stakeholders helped to understand how they perceived the hospital, what they expected of the code of ethics, and how to implement it. All of these were considered when creating behavior standards for stakeholders.

Involving stakeholders in creating the organizational code of ethics encourages dialogue, increases transparency and trust, highlights points requiring attention, reduces conflicts, increases identification with the organization's values, and facilitates code implementation.

## The Ethical Debate on Human Germline Editing

Gabriele Werner-Felmayer  
*Medical University Innsbruck, Austria*

With the introduction of CRISPR/Cas, a biotechnical tool for DNA modification with versatile applications, debates on altering the human germline and thus introducing heritable mutations gained momentum again. While for a long time there seemed to be a common understanding that the human germline would be sacrosanct – which is also reflected in several jurisdictions and regulations – more recently the discourse of whether the germline should be altered gave way to discussing under which conditions and when it could be used in the clinics and possibly beyond. Recently, a group of public interest advocates, policy experts, bioethicists, and scientists raised their concerns over several misconceptions in the debate, called for course direction and advocated for developing meaningful public engagement and empowerment (see Geneva Statement on Heritable Human Genome Editing: The Need for Course Correction by Andorno et al., Trends in Biotechnology 2020, online on 31 January 2020, print version 1 April 2020). As one of the contributors to this statement, I will outline these concerns and present an analysis of the background of the current debate, which is often focusing on technoscientific issues such as precision and risks of the technology but ignoring its ethical and social implications and the fact that engineering the human germline is not just another technical challenge.

## Hungry for Change: Is Big Food the New Big Tobacco and What Can Global Health Law and Ethics Do about It?

Citta Widagdo  
*University of Birmingham, UK*

Obesity constitutes a major challenge that costs society billions in health care and lost productivity, especially in the developing world. While the causal pathways to obesity are complex, commercial drivers allow people easier access to calorie-dense, nutrient poor foods at bargain prices that has affected our built environment. This research seeks to analyze the role of global health law in preventing obesity. It is grounded on public health ethics, positioning that the state has a duty to facilitate healthier lifestyles and to remove inequalities that affect disadvantaged groups or individuals, while minimizing intrusive measures. To answer the question, this research primarily employs legal dogmatics, focusing on global health law and human rights law by assessing various legal instruments that have been developed in the area of obesity prevention to analyze the current international regulatory approach to obesity prevention and the regulatory gap. It also uses comparative analysis with tobacco control by assessing the history of WHO FCTC as a successful legally binding treaty and landmark court decisions to look at the role of courts in improving public health. This research argues that a legally binding health treaty is needed to regulate unhealthy diets and tackle health inequalities.

## Links between Alcohol Consumption and Domestic Violence. Why the Europe Should Focus on Effective Alcohol Policy?

Monika Wilanowska  
University of Lodz, Poland

My speech will pertain to the scale of alcohol problem in Europe, links between alcohol consumption and domestic violence and also European alcohol policy. World Health Organization report about alcohol consumption, harm and policy from 2019 had shown that alcohol consumption in WHO European Region is continuously the highest in the world. It is worth to remember that alcohol consumption is not only individual problem of the addict. Unfortunately, it causes large number of negative social issues. Surely, it is the simplification to say that domestic violence is always associated with alcohol abuse, although in majority of the cases, links between alcohol consumption and domestic violence are obvious. For example, Polish Public Agency of Solving Alcohol Problems had evaluated, that in Poland 800 000 people are addicted to alcohol and 2/3 members of their families could be named as domestic violence victims. Therefore, we could say that in Poland, there are even 2 million of domestic violence victims in the cases when the perpetrator is addicted to alcohol. In most of European countries this problem looks similar. Domestic violence causes various types of negative effects for victims. Undeniably, effective alcohol policy in Europe is needed to reduce domestic violence problem.

## Team-Based Learning in Bioethics Education: Creating a Flexible, Low-Cost, Evidence-Based Curriculum for Trainees in Medicine

Sheria Wilson<sup>1</sup>, Stephanie Lauden<sup>1</sup>, John Mahan<sup>1</sup>, Sandra Spencer<sup>1</sup>, Ashley Fernandes<sup>1,2</sup>

<sup>1</sup>Nationwide Children's Hospital, USA

<sup>2</sup>The Ohio State University, USA

**Background:** Teaching medical ethics is a priority in medical training in the US and around the world. Team Based Learning (TBL) has been utilized inside and outside of medical education with success but its use in bioethics education has been limited, despite its pedagogical strength and the importance of teaching humanistic values and culturally appropriate ethics.

**Activity:** From 2015-18 we created and administered 10 TBL bioethics exercises using L. Dee Fink's "Principles of Significant Learning" and the evidence-based methodology of TBL to pediatric residents. We evaluated the TBL curriculum and report satisfaction scores and qualitative thematic analysis of strengths and weaknesses.

**Results and Discussion:** Pediatric residents, despite limited curricular space, were engaged and satisfied with a TBL-only based bioethics curriculum. We were able to adapt the TBL structure to the situational factors surrounding the rigors and unpredictable nature of clinical graduate education. We offer four "Lessons Learned" for creating and implementing TBL exercises in medical education. Some curricular elements will be available freely online through a grant from the Arnold P. Gold Foundation in 2020-2021. TBL can be used in bioethics to create both individual culturally appropriate exercises and a comprehensive ethics curriculum that promotes both knowledge and humanism.

## Using Neuro-technology to Investigate Crime: Results from Testing on Students and Prisoners

Debbie Wilson  
University of Canterbury, New Zealand

What if you could tell, with 99% accuracy, whether a person was present at the time a crime was committed? What if you could directly ask a person's brain whether it recognized words or images that only someone present at that crime scene would recognize?

Brain Fingerprinting is an emerging neuro-technology that uses an EEG/ERP approach to detect concealed information in the brain. By showing the test subject words related to the crime scene and then measuring the P300 component of the event-related brain potential, testers can determine whether the subject recognizes those words as significant, suggesting presence at a crime scene.

This paper reports on the first independent verification studies carried out on brain fingerprinting, using university students and convicted prisoners as subjects to determine which one in a group of four subjects was present at a particular event.

After discussing the results of this testing, the paper will consider some of the legal and ethical implications of using this technology in criminal investigations and/or in criminal prosecutions.

## Legal Evaluation of Opportunities for a Successful Public-private Partnership in the Polish Healthcare Sector

Weronika Wojturska  
University of Warsaw, Poland

The paper aims to present the results of legal and comparative analysis of the functioning of individual models of public-private partnership under different legal systems, with particular emphasis on Polish regulations.

The use of the PPP formula for investments in healthcare in Poland due to its functionality in the field of financing hospital investments, still requires, due to the limited scale, the search for the most effective solution models. The author's research analysis in terms of profitability and effectiveness of PPP models in health care shows that they pass the exam both solutions that limit the scope of the private partner's responsibility to infrastructure (the building and its surroundings), as well the private sector is entrusted with both infrastructure and public medical services.

As a result of the research on the functioning of the infrastructure and integrated model, the author sets out *de lege ferenda* postulates on the example of regulatory environments and legal frameworks adopted in other countries. It indicates which of the solutions of particular models is the most effective in financing hospital investments, taking into account the specificity and conditions of the national legal order in Poland.

## Core Learning Objectives about Health Professional Involvement in the Holocaust for Health Sciences Students Today

Matthew Wynia, Mark Levine  
University of Colorado, USA

Learning about health professionals' involvement in the Holocaust is important for health sciences students, but this history is complex. Consistent teaching requires a specific set of learning objectives that every student should achieve prior to graduation. These must be discrete, feasible to teach, and important for understanding the relevance of this history for health professionals today.

We convened a multidisciplinary group of advisors and scholars to develop a set of learning objectives, which were then pilot tested with students taking a semester-long course on medical history of the Holocaust.

The proposed learning objectives are that all health professions students should be able to:

- 1) Describe the theory of eugenics, including its frequent relationship to racism.
- 2) List 3 social/economic factors that led Nazi medical professionals to alter their ethics, placing the perceived needs of the German state over the needs of individual patients.
- 3) Describe at least one non-German state or national program of forcible sterilization and its relationship to the Nazi forcible sterilization program.
- 4) Describe medical involvement in the Nazi child "euthanasia" and Aktion T4 programs and how these relate to later programs of mass murder in the Holocaust.

## Ethics and Pre-exposure Prophylaxis (PrEP) for HIV Prevention in China

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<sup>1</sup>Central South University, China

<sup>2</sup>Federation University, Australia

Pre-exposure prophylaxis (PrEP) is effective for HIV prevention, but it hasn't been widely utilized by men who have sex with men (MSM) in China. This study aimed to investigate ethical concerns of PrEP in this population.

It was convergent mixed methods research. Quantitative data was collected through a survey in 255 MSM and qualitative data included 26 in-depth interviews in Changsha, China from March to August 2019. Multivariate logistic regression and thematic analysis were adopted to analyze data.

More than half of the participants (59.2%) demonstrated willingness to use PrEP. However, 118 participants (46.3%) expressed embarrassment and stigma toward PrEP use. Only a few participants (17.3%) indicated that they would not use condoms if using PrEP. Multivariate analysis on the likelihood of decreased condom use was independently associated with being in intimate relationships (P.05) and, anal sex (P0.001) and frequent HIV testing in the past 6 months (P0.01). Themes from qualitative data were misconception about effects of PrEP and condom use, economical concerns and stigmatization of PrEP. Quantitative and qualitative data supported each other.

To make the most use of PrEP, efforts should be taken to solve ethical dilemma.

## Ethical Counseling: The Impact Factor

Gila Yakov, Orit Golan

The Max Stern Yezreel Valley College, Israel

As a result of changes in patient-doctor relations, accelerated technological development, and changes in the nature of medical treatment, new ethical challenges arise in the clinical field.

The therapeutic field is characterized by significant caseloads and ethical complexities. In addition, some of the staff members lack the tools to deal with ethical questions.

Over the years, health organizations have established frameworks for ethical counseling aimed at assisting health service providers in making decisions.

In Israel, ethical counseling exists in the health system as a result of legislation, and in addition, there is a voluntary ethical counseling framework. These frameworks do not provide a comprehensive response to clinical needs. Although these frameworks help address ethical questions, at the moment indices to examine successes are lacking.

In light of these shortcomings, we present a comprehensive model for ethical counseling which includes ethical standards based on a unique approach to ethics - Positive Ethics. This approach includes training through field-based case studies, establishing ethical frameworks for staff, and ethical counseling. We seek to promote measurement of training and improvement of ethical conduct. Identifying initial phases of improvement in the clinical field will encourage the system to invest more deeply in continued implementation of ethical frameworks.

## Informed Consent in Psychiatry: Is the Patient Competent to Make Decisions? Ethical and Medico-legal Issues

Simona Zaami

"Sapienza" University of Rome, Italy

Informed consent in psychiatry is a multifaceted, complex concept: it is in fact essential for the provision of treatments and procedures for the sake of mental patients; hence, it must be necessarily grounded in an appropriate understanding of all relevant and necessary information, thoroughly provided and elaborated on by doctors. Several aspects relative to the provision of information in psychiatry still appear somewhat hazy. Consent is not a form or a procedure, but rather an organic process, a meaningful exchange of information that starts at the moment of first contact between doctor and patient and continues during the course of the treatment relationship. Not impersonal information but authentic communication. The key elements of consent must be painstakingly enforced by psychiatrists. Consent can only be provided by mentally capable and legally competent persons. Competence is sometimes used interchangeably with capacity, although they are different concepts: capacity is but one aspect of legal competence. Clear-cut, enforceable sets of standards to formally assess capacity to consent to treatment are codified in several guidelines, recommendations and pieces of legislation. Compliance with them can help ensure that doctors do not face legal claims and charges of negligence and malpractice.



## Genetic Responsibility

Ruth Zafran<sup>1</sup>, Ayelet Blecher Prigat<sup>2</sup>

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While the availability of over-the-counter (OTC) DNA testing kits constitutes an opportunity for consumers, it also presents a series of challenges for families. The widespread accessibility of such kits, together with DNA databases and social networks, subverts the norms of secrecy and confidentiality that are still prevalent, *prima facie*, in different familial contexts. These include scenarios in which family members seek access to genealogical data and medical data.

We draw on a range of case studies to illustrate both the dilemmas such access can generate and also the shifting meanings of privacy in the realm of genetic testing, including situations in which OTC testing, reveals the identity of a gamete donor or genetic siblings; presents negative genetic findings (such as potential illness) that may have an impact on other family members; produces life-changing surprises, such as a father's discovery that he is not the genetic father of the child he has reared as his own and so on.

The framework of analysis we offer, informed by Helen Nissenbaum's approach of contextual privacy, is aimed at shaping our thinking on the legal issues at stake while distinguishing between, the new kinship and the old kinship and the relevant meaning of "genetic responsibility".

## Deep Brain Stimulation (DBS), Attributability, and Forward-Looking Approach to Moral Responsibility

Przemysław Zawadzki

Jagiellonian University, Poland

Deep Brain Stimulation (DBS) leads to various threats concerning governing, understanding, and experiencing the self by (and of) a person treated with it. Side-effects of DBS include changes to patients' psychological characteristics, sense of agency, or behavioral tendencies (Gilbert & Viaña, 2018). In some cases, patients perform actions unlike any that they would have performed were it not for DBS; some reports such as: "I feel like a machine," or "I feel like an electronic doll" can even be interpreted as expressions of globally undermined agency or/and autonomy (Goddard, 2017). Thus, important question arises of whether patients are morally responsible for actions performed under DBS influence. Recently, Sharp and Wasserman (2016) bring philosophical debate on moral responsibility to practical concerns regarding DBS by applying historical view of responsibility. However, their model deals with an accountability question—whether (and in what circumstances) DBS patients deserve guilt and punishment. In the presentation, I will propose different perspective, in which one asks an attributability question—whether (and in what circumstances) actions can be properly attributed to DBS patient. I will argue that this reconceptualization brings the prospect of constructing a forward-looking account of moral responsibility regarding neuromodulation therapies. Finally, I will consider practical implications of adopting this approach.

## Prevalence of Death in Kosovo Mental Health Institutions, Ethical Challenges: Case Study

Miftar Zenelaj

University Clinical Hospital Service of Kosovo, Kosovo

According to WHO data, at the global level, around 8 million people die of mental illness each year.

Referring to WHO data, the average decrease of the lifespan of people with mental illnesses (schizophrenia) is 10-15 years shorter compared to the mortality rate of the general population, thus the question is what the exact cause of mortality of people with mental illnesses?

This early death is mainly attributed to "natural causes", such as acute and chronic diseases (heart disease, pulmonary diseases, infectious diseases, cancer, etc.) and "unnatural causes" such as suicides, involuntary injuries, smoking, and consumption of various substances, insufficient physical activity, poor diet, socio-economic conditions, and the lack of health care.

In this new era where equality should be determined by ethical and legal norms, and by equality we mean equal health and social treatment for everyone including people with mental disorders, which will have an impact of decreasing or even eliminating risk factors, thus avoiding the death of people with mental disorders.

The research is based on the quantitative analysis of data available at the Mental Health Centers in Kosovo from 2009 to 2019. The relevance and the aim of this study is meta-analysis of mortality of people with mental disorders who have been treated in Mental Health Centers, and our research strategy covers age, diagnosis, cause and place of death of the patients.

## Privacy and Autonomy: A Comparative Case Analysis of Medical Ethical Dilemmas in China and the United States

Hui Zhang<sup>1</sup>, Li Li<sup>2</sup>, Zhenxiang Zhang, Yuming Wang<sup>1,2</sup>

<sup>1</sup>Zhengzhou University, China

<sup>2</sup>Henan Provincial People's Hospital, China

Respect for patients' privacy and autonomy is a common primary principle of medical ethics. Ethical dilemmas in China have often occurred owing to the late development of medical ethics. However, the presence of a mature medical ethics has not completely avoided ethical dilemmas in the US. This presentation discusses four typical cases having significant social impact. First, it compares two cases concerning patient privacy and consent: the "Xinjiang-Shihezi Hospital Case," concerning a patient's use without permission as a clinical teaching object, and the "New York-Presbyterian Hospital Case," concerning the hospital allowing a patient's treatment to be filmed without consent. Second, it compares two cases regarding patient autonomy and potentially life-saving medical procedures: the "Li Liyun Case," concerning a boyfriend's refusal to sign consent for his girlfriend's caesarean, and the "Nelly Vega Case," concerning a hospital's insistence upon a blood transfusion for a dissenting patient. This presentation introduces each case, supporting and opposing views, and social impact in both Chinese cases and both American cases. It then compares and analyzes both the differences and influencing factors of patients' privacy and autonomy in each country from a multicultural perspective.



## Should We Use Bedside Card with Patients' Medical Information in Hospital: An Ethical Dilemma in Clinical Practice

Xinge Zhao, Xiaoju Tan  
The Second Xiang Ya Hospital of Central South University, China

Bedside card is a signboard posted above the hospital bed, including the patient's name, gender, date of birth, ward name, bed number and even diagnosis in some hospitals in China. Bedside card can provide a convenient check and reduce medical error for medical providers; thus, it has been used for many years in Chinese hospitals. However, with the increase of multiple communication channels, more and more patients concern about the privacy of medical records and think the right of privacy might be violated by bedside card, although some hospitals have cancelled the diagnoses on the bedside cards. This study described this ethical dilemma about using the bedside card and put forward some feasible recommendations. First, letting the patients decide whether to share their medical information on the bedside card or not. Second, changing the display method to conceal information confidentiality, such as using abbreviated word especially for diagnosis. Third, utilizing mobile terminal equipment instead of bedside card for medical checking. Above all, it is necessary to clarify that respecting personal privacy should be emphasized as the same as patient safety in healthcare settings, and cultural context should also be considered.

## Vigilance about Possible Organ Trade in Living Donor's Kidney Transplantation

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<sup>3</sup>Croatian Medical Chamber, Croatia

Even in countries with highly regulated organ donation and transplantation, ethical vigilance is strongly required to prevent organ trade (OT). Law could provide opportunistic frame for a hidden lucrative relation for a living kidney donor (LKD). Any paid LKD becomes a victim, even when the donation solves a poor existence. Such humiliating position of a human being is morally unacceptable. Ethical principles should be above any other argumentation. Ethical committees, special assessments, multiprofessional team work-up and relevant criteria based on the experience help in ascertaining "altruistic only" donation. However, rejecting a LKD for a suspicion of OT without real evidence, deprives a recipient from the best treatment, challenging a different ethics. On the contrary, performing the surgery with unsolved suspicion, post festum turned out to be an OT, jeopardizes confidence in physicians and health system. In a broader perspective, national policies should include planned education of citizens about organ donation, transplantation and about immorality and danger of OT. Even broader approach is making effort by a state to manage social conditions that recruit organ sellers.

## "Giancarlo Rastelli" Clinical Ethics Service

Luigi Zucaro, Anna Dalle Ore, Maria Fornari  
Ospedale Pediatrico Bambino Gesù of Roma, Italy

In Italy there was no specific unit to help healthcare personnel to face ethical issues arising in daily clinical practice, until recently. Therefore, Ethics Committee (EC), in addition to assess research protocols, provides Clinical Ethics Consultation (CEC) and offers ethical education; but the latter two are secondary task. The EC shall be composed of members with different skills, of whom at least one third shall not be employed the hospital. Many hospitals don't have their own dedicated EC. Although the Bambino Gesù Children's Hospital in Rome already had its own committee EC, in 2016 the hospital direction decided to introduce a Clinical Ethics Service (CES) to support clinicians to face ethical issues of clinical practice. This CES is composed of a small team and CEC may be required by the patient, his family, the clinicians or other figures involved. The fact that since the CES creation the CEC demand has grown by more than 50% supports the idea that the CES is a more user-friendly tool. We provided 20 CEC in 2018 and 21 CEC between January and November of 2019. CES also provides ethics (plural ethics?) education. We report here our experience and our data.

## Tackling Institutional Ageism in Healthcare

Tom Walker  
Queen's University Belfast, UK

As populations age around the world healthcare systems face increasing numbers of patients living with chronic disease, experiencing multimorbidity, and coping with physical and cognitive decline. Existing systems are not designed to cope with this. The organization of specialties, the education of doctors, and the allocation of resources were designed with a different world in mind — one where the focus is on curing those with acute conditions, preventing the spread of infectious disease, and caring for children. As a result, the structures and priorities of these systems have built into them attitudes that unfairly discriminate against older adults as a group. That it, they are institutionally ageist. This represents one of the biggest, but often unseen, sources of injustice in contemporary medical practice. Tackling this injustice is challenging because it requires both institutional change (which can be blocked by existing interests and inertia) and tackling the ageism that in most places characterizes society as a whole. Given its systemic character a societal or systems focus is needed. That cannot be done using the individual values of autonomy and beneficence. Instead, it requires emphasizing the more communal values of solidarity and dignity.

## **Disasters and Terrorist Attacks: The Need for Special Medical Legislation for the Victims and the Investigating Team**

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Eva M. Kereszty  
*University of Szeged, Hungary*

The number and the condition of the victims – survivors and dead – in a disaster or terrorist attack or even in a transportation accident may be a huge challenge for the rescue teams, for the health care facilities and the police teams. The identification of the victims and the health services follow special rescue protocols to reach a quick and acceptable result, but numerous regulations make it hard when we follow the traditional health legislation tools.

The presentation analyses the contradictions of the unnatural death regulations, the problems of the patient's rights, the data protection issues, and the role of the health data in the non-medical investigation process.

The analysis is basically built on the Hungarian health legislation and the Interpol's Disaster Victim Identification (DVI) protocols, but also takes into consideration the multicultural and multinational background of the potential victims. Problems are enlightened through recent examples.

Our conclusion is that the medical law must be prepared for the handling unique situations with respect for the traditional patient's rights, whilst in the interest of the society we have to establish specific legal norms.



# Abstracts Poster Presentations



## Benito, the 'Vaccine Child' of the Smallpox Boat

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This poster aims to remember the almost forgotten deed of 22 orphaned children taken from Spanish hospices who toured the world in 1803 to extend the vaccine against the then lethal smallpox. It was the sacrifice of these children that directly saved more than 250,000 people - and more than half a million indirectly - from smallpox, which decimated cities, caused death, and in the best case, blindness and facial marks of for life. Thanks to Benito and the other 21 children, humanity's first medical expedition would be a success. The expedition was commanded by military doctor Francisco Javier Balmis, with experience in vaccination. The method was revolutionary and incredible: immunize by contagion. Why were these little ones chosen and not adults for such a company? In 1798, the English doctor Edward Jenner had discovered that milking women on farms in northern Europe were infected with a mutation of human smallpox: that of cow. This contagion, which produced some mild fevers in the human body, caused him not to catch on them the lethal variant that ravaged entire cities and that had been wreaking havoc for two years in New Spain (Mexico). The success of the already known as vaccine was greater if the person carrying the virus had not had any contact with diseases, and hence the choice of children.

## Law and Ethics in the Online Sale of Medicines

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The sale of medicines through the internet or other distance selling procedures worries Health Authorities since the misuse of such products can mean citizens' access to medicines without guarantees of quality, safety and efficacy or accompanied by wrong information. The websites and the Apps for the sale of medicines proliferate, both subject to medical prescription and not subject to it, which do not comply with the provisions of current legislation. Even large distribution platforms, such as Amazon, are selling health products online.

The requirements for the legal online sale of medicines in Spain are specified in Royal Decree 870/2013, November 8, which regulates the distance selling to the public, through websites, of medicines for human use not subject to medical prescription, transposition of Directive 2011/62 / EU, of the European Parliament and of the Council, of June 8, 2011, which modifies Directive 2001/83 / EC.

This paper aims to critically analyze this European and Spanish normative reality.

## Facial Phenotyping and Deep Learning: Ethical Challenges

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<sup>2</sup>Hospital de São João, Portugal

Computer assisted image analysis using deep learning has gained attention in the medical field. Automated facial analysis technologies using deep convolutional neural networks have proven useful in diagnosing a few disorders and some genetic syndromes with high sensibility and specificity, even outperforming physicians. The authors have conducted a separate search of Pubmed, Web of Science and Scopus databases using the keywords "facial phenotypes" and "deep learning" and have independently analyzed the results and selected the literature from inception to November 2019. An independent review of the literature was performed in order to identify the current use of this technology in the recognition of specific facial characteristics or dysmorphisms in phenotype-genotype correlation studies and analyze its ethical implications.

While this technology seems to be clearly beneficial assisting medical and genetic diagnosis, its general public use can potentially incur in discriminatory actions and monitoring or regulation avoiding abuse seems mandatory. Using identifiable image data needs directives. Transparency remains an issue in using artificial intelligence in clinical practice and this technology also does not clearly explain how it processes in order to reach a diagnosis. Also, differences in ethnicity and in age currently significantly affect this technology's sensitivity. Expert physician supervision is required to balance the algorithms' results in individual patients.

## The Role of Human Rights in the Phenomenon of Illegal Landings: A Retrospective Study of Southern Italy

Isabella Aquila<sup>1</sup>, Matteo Antonio Sacco<sup>1</sup>, Carmen Scalise<sup>1</sup>,

Angelica Zibetti<sup>1</sup>, Fabrizio Cordasco<sup>1</sup>,

Martino Maesani<sup>1</sup>, Umberto Rosini<sup>1</sup>, Francesco Maria Galassi<sup>2</sup>,

Elena Varotto<sup>2</sup>, Santo Gratteri<sup>1</sup>, Pietrantonio Ricci<sup>1</sup>,

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Immigration represents a phenomenon of great social impact. Every year, around 70.8 million people worldwide left their country. In 2019, there were 125,472 arrivals in the Mediterranean Sea and 1327 immigrants are currently dead or missing [1]. Despite the increase in the phenomenon, there are no unequivocal statistical data about the reasons for refugee status. We propose a retrospective study performed on a sample of 500 migrants who landed in the Mediterranean Sea and applied for a residence permit. The data were collected through interviews carried out with the help of an interpreter. Respondents were asked to explain the reason for abandoning their country. The collected data were classified according to gender, country and motivation. The retrospective study revealed that: 58.4% of respondents claimed violence related to terrorism, religious and political persecutions; 32.8% declared unjust judicial or personal persecutions and homosexuality; 5% claimed female circumcision, mistreatment, sexual violence, ethnic discrimination, war, or illness. Only 3.8% declared poverty. Our study shows that the violation of human rights has a decisive impact on the phenomenon of migration. We emphasize the promotion of initiatives to defend human rights in these countries in order to reduce illegal landings and the number of deaths related to the phenomenon [2].



## Ethical Aspects in Prehospital Setting

Jordano Araújo  
University of Porto, Brazil

**Background:** Prehospital care presents unique ethical challenges. The principles of autonomy, nonmaleficence, beneficence, and justice are often difficult to observe in the uncontrolled environment of prehospital care. The aim of this study is to review the literature on the ethical aspects of prehospital care, with a special focus on Brazilian reality.

**Methods:** A non-systematic literature review was performed in Pubmed, Scopus and Web of Science databases with the following terms: "prehospital care" and "ethics". In addition, a real-time follow-up was conducted on the period from August to September 2019 of an Emergency Medical Service (EMS) dispatch center in Federal District, Brazil.

**Results:** The principle of justice raises questions mainly in the issues related to attendance and dispatch of solicitations. The calls, in the Federal District, are filtered by a medical regulation center linked to the EMS. The decision whether or not to send resources (which are scarce) often involves difficult decisions. In prehospital care, consent is not always expressible due to the patient conditions. Confidentiality is also compromised, as often attendance is done on public spaces. Another complex situation is the refusal of care by the patient, who is sometimes in an abnormal mental condition, due to illness or intoxication. One last important aspect to be analyzed is the ethics of research in the prehospital environment. Since patients are often in extreme situations and unable to consent, is afterword consent enough in clinical trials?

**Conclusion:** Prehospital environment presents unique challenges to the practice of care based on ethical principles. Principles of fairness in screening, autonomy in consent and research, and difficulties in following end-of-life guidelines are of special concern.

## Benefits and Risks of Bioprinting Application According to Medical Specialists' Opinion

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**Background:** Bioprinting technologies are an object of increasing attention on the side of medical specialists due to the possibilities which it provides for the treatment and improving quality of life of patients. Therefore, we aimed at studying medical specialists' opinion on some benefits and risks related to bioprinting application.

**Methods:** We conducted an anonymous survey among medical specialists (n=129) - physicians (62.8%), doctors of dental medicine (11.6%) and pharmacists (25.6%) aged between 24 and 56 years (mean 39.28±0.74). The questionnaire included various (ethical, legal) aspects of bioprinting application in healthcare.

**Results:** We found that 72.1% of participants consider provision of transplantation organs its greatest advantage. Other significant advantages for the respondents are the possibility of medication testing on 3D models (67.4%) and improving patients' quality of life (58.1%). The main disadvantages according to medical specialists are the danger of an uncontrollable self-improvement of the human body (58.1%), disruption of normal cell function and a potential unpredictable immune response (46.5%).

**Conclusions:** From the results obtained we found that the benefits of bioprinting application in healthcare significantly exceed the occurrence of potential problems. It is necessary to unite all interested parties around establishing an international regulator that would observe strictly the reasonable application of bioprinting.

## The Moment of Diagnosis of Neuromuscular Diseases: Systematic Review

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**Introduction:** The importance of the patient-physician relationship has been discussed since the dawn of medicine and throughout history the patient has never ceased to be the main focus of the medical act. The diagnostic moment, especially when it is a genetic and neurodegenerative disease, has immeasurable value in the autonomy of these patients and their families.

**Objectives:** To verify the presence of studies related to the time of diagnosis of neuromuscular diseases that began in childhood and adolescence and to correlate their findings with the ethical principles of beneficence and nonmaleficence.

**Methodology:** Systematic review searching the Pubmed, Bireme and Scopus portals in November 2019, whose descriptors were ("Muscular Diseases" OR "Neuromuscular Diseases") AND "Truth Disclosure".

**Results:** No randomized study, systematic review, observational or intervention study was found. A single filtered article dates from 1983 and focused on Duchenne Muscular Dystrophy.

**Discussion and Conclusions:** The wound caused in beneficence and not maleficence by improper communication, exemplified by superficial information, generalizations and diagnosis without the presence of the spouse, for example goes beyond the principle of autonomy, since without proper understanding of the context in which they are inserted, there is insecurity in decision making.

## Reflections on Bioethics in Front of Environmental Issues

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Environmental ethics became widely used from the 1970s onwards in research, political intergovernmental debates and society, with reflections on human actions on the environment, stimulated by the capitalist system. As a result, these actions have led to and cause global environmental problems. Bioethics is considered a broad subject with applicability to any human action. Therefore, we must use bioethical principles to strengthen the universal values of respect for the person, fundamental rights and dignity. The mass growth of the world population, exploitation of natural resources, pollution, poverty and anthropocentrism founded by Rene Descartes (1596-1650), the latter which man sees nature as object or subject, strengthens contemporary culture towards paths of ecological and civilizing crises. Society lives at an accelerated time, making excessive use of technologies with negative effects on humanity and the environment. It is necessary to act and reflect on human actions versus nature and change the way of thinking about the environment, it is another paradigm with bioethics to target humanity as part of nature.

### **A Bioethical Discussion about the Legal Requirements for Blood Donation by Homosexual Men in Brazil**

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Introduction/discussion: In Brazil, a blood donation is a voluntary act that needs to meet several prerequisites, including temporary and permanent impediments. Among others, the National Health Surveillance Agency (ANVISA, in Portuguese) establishes that men who have had sex with other men and/or their sexual partners, in less than 12 months, cannot donate blood, based on the argument that the risk of sexual transmitted diseases in this group is 19 times bigger than in the rest of the population. Given that, through a literature review, this article discusses the boundaries between evidence-based medicine and bioethics and the discrimination that happens with homosexual men about blood donation.

### **The Controversy of Initiating Artificial Nutrition in Palliative Care: Is it a Basic Human Need or a Life-sustaining Treatment?**

Sol Benbunan  
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The field of palliative care has experienced a breathtaking growth in the last decade.

Artificial Nutrition and Hydration (ANH), being part of the palliative care field, has been disregarded by literature. However, as Hippocrates said: "Let food be thy medicine, and let medicine be thy food." Accordingly, this paper not only emphasizes on the importance of the ethical dilemmas entailed by ANH, but also questions whether it can be considered a human need or a life-sustaining treatment.

To do so, this paper primarily explores the definition and limitations of palliative care in order to understand why some physicians and bioethicists consider ANH a treatment while others support its designation as a palliative care measure.

A section of the paper is then dedicated to the vastly discussed fact of withholding and withdrawing ANH in order to introduce the ethical and moral principles within ANH.

Finally, the sociocultural connotations of food and drink will be exposed in order to understand not only the reason why it is easier to withhold than to withdraw ANH for physicians, but also the reason why patients accept or even ask for ANH *prima facie*.

Besides giving a medical and philosophical perspective of this issue, this research proposes solutions in cases where ANH is not an option.

In conclusion, this project demonstrates that ANH is not only a life-sustaining treatment but an actual human need.

### **Bioethical Principles in the Work of Occupational Health Specialists**

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In the constantly evolving labor market with the advent of new technologies and forms of work, ethical problems in the work of occupational health specialists become more complex. Ensuring safe and healthy working conditions requires mutual efforts by occupational health services, employers, employees and their representatives, trade unions organizations and public authorities. In the practice of occupational health professionals, in many cases, ethical issues arise related to the health and safety of workers at individual and group levels. The purpose of this study is to examine the role of bioethical principles as defined in the UNESCO Universal Declaration on Bioethics and Human Rights in the work of occupational health professionals.

### **Surgery for All: An Ethical Analysis of Approaches to Increasing Access to Safe Surgery in Low-income Countries**

Anna Berman  
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While most people in high-income countries have access to safe surgical care, less than 1% of the population in low-income countries have such access. Numerous articles published in global health journals have analyzed approaches to addressing this crisis. However, current literature has not focused on the utility or the bioethical issues that would arise by implementing various approaches. This project addresses this gap in the literature by conducting a utility analysis of several options: inaction, increasing surgical humanitarianism, training more doctors in their home countries, training people from developing states in high-income countries, and implementing community-led task-sharing programs. This analysis finds that task-sharing best maximizes utility and other approaches cannot meet the extensive need. This work also examines bioethical issues in task-sharing to determine whether it is an ethically advisable approach for increasing access to surgical care. Considerations include matters of resource allocation, physician and patient autonomy, culturally appropriate informed consent, quality of care, respect for cultures and communities, and medical neo-colonialism. This research finds that task-sharing is the method of increasing access to surgery with the greatest utility and that community-led implementation could strengthen national medical systems, which reduces medical neo-colonialism.

## A Pro(longed?)geny: Ethical, Legal, and Social Implications of Post-Menopausal Reproduction (PMR) in India

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A recent occurrence of an elderly woman giving birth to twins in Andhra Pradesh, India had gained controversy. In light of the lack of a legal bar on PMR, this paper examines the ethical and social considerations embedded in the debate around the complex ethical milieu that are sui generis to the Indian context. While on the one hand, the possibility of PMR fuels motivations such as the feeling of achievement and satisfaction, it also feeds into the culturally significant "role-fulfillments" associated with and dependent on the existence of (male) heirs. A gamut of complexities unfold as one examines, amongst other things, the debates around women's agency, contextualizing them to the Indian society. After surveying a variety of arguments for and against - both generally and specific to the Indian context - this paper evaluates the ethical and the legal regulatory proposals. Specifically, it considers whether there exists a moral and consequently a legal obligation on doctors to ensure that they provide Post-Menopausal Women with ART.

## The Privacy and Medical Records in Italy

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The concept of privacy has undergone a radical change over the years, it went from a perception of privacy as individualistic and negative where privacy is equated to the right to be left alone, to a positive perception of person's awareness to have their fundamental right and dignity be fully respected.

The European regulation of personal data (GDPR) reinforces the protection of privacy, especially in the health sector, and in particular the handling of genetic data, biometric data and health related data and which is only possible with sound consent of the person concerned. Healthcare workers are therefore called upon to conform with these requirements facing with no easy tasks, having to pay particular attention collecting the sensitive data, in management of these data and their careful protection in line with the GDPR.

Likewise, the Italian legislation envisage that in special cases such as voluntary interruption of pregnancy, treatment of drug addiction, protection of people with AIDS, clinical medicines experimentation, treatment of genetic data, that the anonymity of the patient must be guaranteed.

The authors in their study are mindful that these issues represent critical and necessary step to ensure that the dignity of the person is fully respected.

## The Implications of Government and Public Access to a Commercial Genetic Database

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Genetic genealogy is a field in family history with important bioethical dilemmas. With lower costs one can get a swab test that provide information about genetic ancestry and preventive health diagnosis. Bioethical and legal considerations arise from obtaining and sharing genetic genealogy tests results, especially in the fields of privacy, confidentiality, informed consent and justice.

Direct-to-consumer (DTC) autosomal genetic tests have reached millions of individuals. DTC providers or third-parties services offer the possibility to find genetic relatives accurately, through analysis of the raw genotype files.

Forensic databases have been used by law enforcement searching for identify close relatives of the perpetrator from a crime scene sample, through controlled databases and rigorous regulatory standards. But now Law enforcement agencies are using third-party consumer genomics services to find even distant relatives. It's important to clarify that "a genetic database needs to cover only 2% of the target population to provide a third-cousin match to nearly any person" (Erich, Shor, Pe'er, & Carmi, 2018).

It's clear that there's a real risk for employment or insurance discrimination and forensic research through reidentification of genomic data. Important ethical issues for DTC autosomal genetic tests are raising and special regulatory norms must be created including better informed consent and limits on forensic criminal genealogy through regulatory standards.

## Madam and Eve: Genetic Bimaternal Parenthood and the Enhancement of Justice

Isabella Braga

Yale University, USA

Though for decades artificial reproduction technologies have enabled infertile heterosexual parents to birth their genetic offspring, same-sex parents are forced to choose one partner to pass genes to their child. This is because, until now, both a sperm and egg have been required for child-bearing, preventing many members of the LGBTQ+ community from bearing a child with a genetic relationship to both parents. This paper addresses newfound methods of bimaternalism – embryos created from an oocyte and an embryonic stem cell – and how furthering this research enhances justice in society. Specifically, this paper argues for the furtherance of bimaternal parenthood despite the current failures of bipaternal parenthood research. Then, Beauchamp and Childress' four principles of bioethics are utilized to support bimaternal parenthood research, with an emphasis on justice in a Rawlsian framework. Potential objections are rebutted, followed by brief recommendations for further action. This research demonstrates that the pursuance of bimaternal parenthood is necessary for a just society. Furthermore, this paper highlights an as-of-yet undiscussed revolutionary reproduction technology with the potential to destroy the biological barriers of same-sex parenthood, carving a more just world for millions and redefining our notions of genetic parenthood.

## Waging a Continuous War: An Analysis of Pro-Life and Pro-Choice Ethical Discourses

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Abortion has been widely debated in the field of politics, religion, and ethics especially since the 1973 Supreme Court decision in *Roe v. Wade*. Existing literature concerning abortion ethics often focuses on the legal, constitutional justifications or limitations of abortion in tandem with meta-ethical debate on issues such as fetal personhood. However, these perspectives have not taken into consideration the contributions that pro-choice and pro-life movements have made to abortion ethics since their rise in the mid-20th century. This research examines various types of media such as political speeches, opinion pieces on blog posts, and video media to determine common pro-life and pro-choice arguments; this paper then analyzes these common arguments to determine whether or not they are founded on fundamentally similar or different normative ethical frameworks. This research argues that pro-life and pro-choice arguments operate on fundamentally different normative, ethical theories. These foundational differences thus contribute to the consistent political split between American citizens and their affiliation with either movement. In conclusion, this project shines new light on how the American schism surrounding the permissibility of abortion may one day be mediated via discussion on a consistent ethical platform.

## Collaborative Project between a Comprehensive Cancer Centre and an Ultraperipheral Regional Health Centre

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Telegenetics has become an attractive method to deliver genetic counseling and testing to remote areas. Traditional in office counseling may be the most appropriate option for several patients but there is a growing acceptance for telegenetics when one considers 1) the rapid necessity of testing for oncological patients in a time of personalized therapeutics and prevention 2) the benefit of evaluation by reference genetic centers with more expertise and data on rare disorders.

Accessibility and convenience is on the telegenetics side weighed against questions like: methods to be used when providing the service (telephone, videoconference or whatever method the patient chooses), tools for confidential information sharing (email, fax, others), appointment arrangement and equipment set up, exclusion criteria for distant counselling (because of age or handicaps), disadvantages of not using face to face communication for bad news, how to obtain written informed consent, and many others.

The authors describe the physical, legal and ethical limitations found during the implementation and completion of a research project based on distant genetical counseling of an ultraperipheral region. Finally, the protocol used for overcoming or minimizing all the barriers identified is presented and major considerations are pointed out.

## Is There Ethics, When Language is Incomplete

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Wittgenstein's philosophical concept of the language game argues that the meaning of words depends on how they are used. As ethics is highly dependent on the specificities of language to reveal its meaning and implications, Wittgenstein's language game exposes the need not just for clarity of language but for serious attention to be paid to meaning in different contexts. We argue that in its current formulation, bioethics, even critical bioethics, typically fails to capture the ethicality of an exchange, its ethical imposition on the mediators of the exchange and others, due to the necessary incompleteness of the language it uses. To investigate the significance of this incompleteness of language, four thought experiments were posed to research participants: Singer's drowning child thought experiment and three researcher-formulated questions on environment, poverty and biotechnology. Through a framework drawn from postcolonialism and critical pedagogy, the responses of the participants were analyzed so as to explore the implication of the current language of bioethics to the lived experience of those who are the subject of thought experiments in real-world settings. The results of this research aim to add to what is known of the importance of language for bioethics.

## Ghost in the Delivery Room: The Posthumous use of Adolescent Gametes by Parents

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It is heavily argued that the serious decision regarding the posthumous use of gametes stored for fertility preservation is further complicated when the deceased is an adolescent. Current recommended guidelines and literature regarding the posthumous use of gametes have not adequately addressed the specific issues of adolescent gametes or use by parents. This project addresses such use with the overarching crux of the argument resting heavily on the discussion of the ethical reliability of parental motivation and the potential existence of self-serving interests when faced with the loss of a child. Though the partner of a deceased adult may have indisputable knowledge of the ante-mortem interests of their partner, the parent of a deceased minor child cannot truly affirm this insight considering the value of reproduction is mitigated by the child's age and cognitive functioning. In conclusion, this project sheds new light on the applicable use of current standards regarding the posthumous use of adolescent gametes and suggests that when parents are afforded the right to posthumously procreate a child "for" their child, a blatant disregard for the principle of non-maleficence exists and there is one foot deeply planted at the top of a slippery slope.



## From the Perspective of Spine 3d Navigation Surgery to See the Medical Law Issues Arising from Smart Medical Care

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**Purpose:** Smart health system includes products with artificial intelligence, individualized treatment plans based on genes, and the usage of high-tech equipment. The popularization of smart medical care will lead to new legal issues. In this study, with the aid of questionnaire about 3D spine navigation system, we try to evaluate surgeons' concept about medical ethics and law in smart medical care.

**Materials and Methods:** There are 6 questions about smart medical care in the google form. The first three questions asking about responders' demography are single or multiple-choice. Question 4 to 6 ask their opinion about the impact of smart health care on healthcare quality, health custom and medical level. These are open essay questions. Fifty neurosurgeons from different hospital were selected to reply the questions.

**Results:** Forty two of the fifty neurosurgeons reply their answers. 62% doctors report their hospitals have 3D spine navigation equipment and 74% report to have experience. In patients' criteria selection, high cervical location, cervical pedicle screws, and deformity surgery were most favored. Factors that affect smart medical care as a medical custom include the penetration rate of equipment, whether it is covered by health insurance, whether there is sufficient empirical medical evidence, and whether it is routinely used by most physicians.

**Conclusion:** Nowadays, the judgment of medical malpractice changed from medical customs to medical level. The usage of smart medical care equipment in daily practice increases both medical level and patients' cost. Their requirements for good results also increase, which promotes the probability of medical disputes. It is worthy for clinic physicians to know that smart medical care, not only improves medical quality, but also increases the doctor's duty of care.

## Bioethics and Medical Ethics in Medical Education

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The teaching of bioethics, medical ethics, and human rights are essential for good professional practice, knowledge of medical humanities has been of great relevance and included in medical education in Brazil.

The national curriculum guidelines for medical courses included ethical and humanistic dimensions in order to develop in the undergraduate sense humanitarian, multi-professional, multidisciplinary and multicultural responsibilities. The medicine course at the Amazonian metropolitan university center in Belem do Para uses the teaching axis of the humanities in medical education, articulated with the interaction with the axes-interaction-teaching-service-community and management (lesc) and scientific initiation.

The module aims to recognize the history of medicine, being a doctor and medical practice, human diversity, and professional ethics, the health problems of the individual, family, and community. Reflects on the main challenges of bioethics in contemporary society; identifies and applies the fundamental principles of bioethics: beneficence, nonmaleficence, autonomy, and justice; guides the professional practice of medicine through knowledge and reflection of national and international guidelines, codes, laws, declarations, and recommendations regarding the practice of medicine and health.

## Crispr-Cas9 and Gene Editing: Is the Loss of Genetic Identity the Price for Perfection?

Fabrizio Cordasco, Carmen Scalise, Matteo Antonio Sacco, Martino Maesani, Umberto Rosini, Angelica Zibetti, Pietrantonio Ricci, Isabella Aquila  
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"Gene editing" identifies the genetic engineering procedures through which it is possible to modify gene sequences in order to eliminate, correct or replace specific DNA fragments. Since the 1960s, with the discovery of recombinant DNA, bioethicists have studied the risks deriving from the possibility of manipulating DNA molecules. The necessity to regulate DNA modification research led to the 1975 Asilomar Conference on Recombinant DNA, during which guidelines on biomedical research were developed. CRISPR-Cas9 (Clustered Regularly Interspaced Short Palindromic Repeats) identifies a short RNA sequence designed in the laboratory able to identify a precise genomic region, which can then be removed with other sequences through enzymatic processes (endonuclease enzyme Cas9). Currently, the main doubts of the bioethical community concern the application of the CRISPR technique on gametes and embryos, due to possible long-term effects. This study highlights the risks associated with the application of the CRISPR-Cas9 technique to germ cells, including the possibility of introducing unknown mutations in the repaired sequences, and the worrying possibility of dangerous drifts towards the "designer babies" or rather children genetically carved to have certain characteristics considered desirable from parents.

## Post-Mortem Insemination and Embryo Transfer: Analysis of Portuguese Law and Public Policies

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The Portuguese law of medically assisted reproduction prohibits post-mortem insemination. Post-mortem transfer of ex uterus embryos is also prohibited, with one exception: a previous written parental project. Nevertheless, if a child is born in violation of the rules, she is still considered the legal child of the donor. Grassroots movements have been successful in convincing some Portuguese lawmakers to make some changes, and there is currently a project under discussion. This project intends to allow post-mortem insemination. We believe that there is an oversimplification of the problem and that adequate changes to the Portuguese Civil Code need to be made to allow the child born in such circumstances the same protection afforded to others. We propose to analyze these problems in light of the Constitution and of international law. We also touch on the broader questions of the future child's best interests and the States' justification for regulating reproduction.



## Relationship of the Aggressor with Victims of Sexual Violence

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Sexual violence against women is a serious offense that is reported to the Health Surveillance. A retrospective cross-sectional study based on the analysis of compulsory reports of rape victims generated at the Sanitary Surveillance Service of the Federal District Secretary of Health, Brasília, from January 1, 2012 to December 31, 2018. The relationship of the offender with victims of sexual violence was classified according to the age of the assaulted woman; children under 15 years of age, from 15 to 19 years of age, from 20 to 29 years of age, and over 29 years of age were analyzed. As for the relationship of the offender with the victim, parents, stepparents, siblings, or spouses were defined as familiar, boyfriends, friends, strangers and, others, as unfamiliar. The percentage was disseminated according to each type of the offender's relationships for each age group and was assessed yearly. In most cases, the assaulted woman was under 15 years of age (58.5%), followed by 15–19 years of age with 16.5%, 20–29 years of age with 13.3%, and those 29 years of age or older with 11.9%. The percentage index showing the familiar offender was 38.7% in the case of victims under 15 years of age, whereas the unfamiliar offender was 48.7% in the age group corresponding to those over 29 years of age. A total of 74.7% of reported cases of sexual violence corresponded to children and adolescents mainly assaulted by siblings. The main offender of the adult woman was unknown.

## Ethics of a Nutrigenetic Study Focusing on Genetic Information in Lifestyle Changes

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This study was one part of a "Genetic Information as a Lifestyle Change Motivator" project in Finland. The project aimed at assessing the effects of disclosing genetic risk information (APOE allele status) on lifestyle changes. The ethics sub-study pursued perceived benefits and concerns of the participants.

An open-ended questionnaire was given to the participants (n=240) at the last contact meeting of the project. Responses to the questions: 1. "For you, what has been the best thing in the study?" 2. "Has the study raised any concerns? If so, what kind of concerns?" were analyzed using summative content analysis.

Out of 192 returned questionnaires, the first question was answered in 185 and the second in 170. Major categories of perceived benefits: i) received information and test results (90.2%), ii) positive health behavior changes (29.7%), and iii) psychological benefits (7.6%). Majority (129/170; 76%) mentioned that the study raised no new concerns. Major categories of concerns raised: i) current health status and lifestyle (12.3%), ii) gene test result implications (11.2%).

Benefits reported were in accordance with the desired outcome of the project. Concerns, particularly those related to disclosure of genetic information, need to be addressed in future studies for conducting ethically good research.

## Human Rights, Global Health Policy, and Coercion in Mental Health

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The application of human rights frameworks is an increasingly important part of ongoing efforts in global mental health. Much of this has been driven by several influential policy instruments, including the UN's Convention on Rights of Persons with Disabilities (2006), as well as the WHO's Quality Rights Tool Kit (2012) and Mental Health Action Plan for 2013-2020 (2013). Despite these important developments, however, much more needs to be done to strengthen human rights protections, in both high income and low- and middle-income countries. This presentation focuses on a critical part of this broader challenge, which is the question of how best to regulate and reduce the use of coercive measures. Human rights violations have generally been an under-researched topic in academic psychiatry, but certain issues have begun to receive sustained attention, particularly stigma and discrimination, and there is now a large literature on coercive measures in psychiatry (focusing on the use of involuntary commitment, seclusion, restrain, and forced medication). This research represents a useful resource that can help guide tractable solutions in real-world settings. These issues are evaluated from the perspective of global health governance, and several policy correctives are recommended in order to improve the monitoring of human rights violations, guide national-level mental health legislation, and strengthen local health systems.

## The ethics of Job Well Done: A Systemic Paradigm for Clinical Risk Management

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According to WHO Global Patient Safety Action Plan 2021–2030, health care systems will have to implement clinical risk management activities to improve patient care, increasing real-time reporting systems to better understand the probable causation.

The COVID-19 pandemic, revealing the concept of "widespread medicine", has shown the limits of a linear logic and the need for a theory of complexity. In this scenario, enabling technologies, such as AI, Internet of Things, robots and big data can support public health interventions. However, we have need to use Big Data, not limiting their use to data correlation but also to their interpretation.

For this reason, we assume that clinical risk management should also change paradigm by adopting a systemic thinking to pursue the safety of care through a multidimensional perspective.

The ethics of Job Well Done applied to Clinical Bioethics allows to evaluate professional action starting from its Quality as a prerequisite for a relationship with the patient that is respectful of the virtue of Justice and Prudence. The ethics of Job Well Done instead of giving an opinion on events that have already occurred (consequentialism), proposes a bioethical co-working because it suggests the best way to act from a scientific point of view.

The impact on Public Health involves combining the quantitative dimension with the qualitative one in a systemic dynamic, that is a qualitative/quantitative evidence based clinical risk management.

## What Forms Should I Choose When Applying a New Clinical Study Involving Cannabis?

Michal De-Wolf, Ornit Cohen, Julio Wainstein, Alon Roiz, Anat Engel  
*Edith Wolfson Medical Center, Israel*

Whenever someone following Israel's guideline for human medical studies, he should know the ethical review process depending on your study, both by different forms and sometimes different committees. As a result, it derives a different approval timeline for each clinical study. Medical cannabis clinical studies must be evaluated through a combined way of working to approval. The first is the common, thought Institution Ethics Committee (IEC) and the Ministry Health (MOH), the second is direct to the Medical Cannabis Unit.

Over the past 10 years, a linear increase in clinical trial publications involved medical cannabis, appeared. While in the pipeline the ClinicalTrials.gov website point currently on 173 clinical studies in several stages, less than 10 recruiting in Israel.

Even though medical cannabis studies are not the majority, the demand for a special way of approval. A new application is filled in parallel to feasibility evaluation in the Medical Cannabis Unit Forms according to national procedure 108 and to IEC new study drug application forms. While the feasibility application relates to production issues, the clinical study application relates to the identified informed consent.

The time frame for medical cannabis clinical study approval can range from 6-24 months. Since these are new era studies include unknown risk for a very ill population, including children, the combined way of working to approval is aimed to protect patients as possible. With that say, there is a need to simplify new applications using electronically combined system that would influence the time to approval as well.

## Informed Consent in Dentistry

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The practice of obtaining informed consent prior to treatment is an act which enshrines the ethical principle of respect for patient autonomy. Historically, informed consent was conceived as a tool to fortify the clinician's credibility against tortious claims in addition to protecting the patient's right to self-determination. Decades later, the steady rise in cases of medical negligence make it all the more pressing for clinicians to be cognizant of the importance of informed consent.

In dentistry, consent is a poorly addressed topic, as evidenced by the lack of literature on the subject. The ambiguity in deciding which procedures or treatment require formally written informed consent puts the patient at risk by omission or misconception of important information to facilitate decision-making. The safeguarding of patients against inadvertent unscrupulous practices whilst defending the dentist against untoward malpractice litigation fuels an acute need for comprehensive guidelines as reference for dentists in their daily practice.

In Malaysia, there appears to be no clear recommendations on the standards expected of dental practitioners in obtaining consent. Therefore, a holistic review of literature on the universal standards of informed consent in dentistry is much needed to develop guidelines on best practices in dental informed consent.

## Answer's Capacity and Accurate Guarantee in Evaluation Activity: Experience of an IRB in Argentina during COVID-19 Pandemic

Maira Dolera Lembeye, Maria Romeo, Daniela Moraes Morelli, Ana De Pablo, Paula Micone, Lourdes Bertolino Eliff1, Rodolfo Keller, Silvio Torres  
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Overcoming the disruption caused by the Covid 19 pandemic and the long-lasting restrictions in Argentina forced our IRB to reorganize processes facing the promptness in the evaluation requirements during the health emergency.

**Aim:** To describe the incorporated changes in operational processes and the results of the evaluation activities during the pandemic.

**Case report:** The meetings changed into virtual weekly modality; the Committee's decisions about Covid-19 protocols were given in a maximum 72-hour period. Electronic investigators and certifying officers' signatures were validated. We adjusted to Argentine regulatory recommendations regarding limitations in patient's recruitment, informed consent obtainment and ongoing protocols monitoring.

**Results:** During 2020, we evaluated 102 projects of which 37% were Covid 19 related. 87% had a favorable report, 9% did not answer back to IRB changing or clarifying requirements and 4% were rejected due to methodologic weaknesses or informed consent performing limitations. The average evaluation time for regular studies was 17 days and 10 for Covid 19 protocols, respectively.

**Conclusions:** We guaranteed evaluation continuity without interruptions even at the critical moments of the pandemic. Response time optimization due to operational transformation, keeping evaluation accuracy, was achieved.

## Informed Consent on Clinical Training: Students and Teachers Perspectives

Ivone Duarte, Rui Nunes, Hernâni Gonçalves, Cristina Costa Santos  
*University of Porto, Portugal*

Informed consent is one of the central concepts of present-day medical ethics. The right of patients to make decisions about their healthcare has been considered fundamental in legal and ethical statements throughout the world. Patients' contribution is fundamental to the complete medical education. The aim of the study was to know the conduct of medical students and their teachers regarding patients consent and discomfort because of the student's involvement.

An electronic questionnaire was elaborated and sent to medical students and a similar questionnaire was sent to the teachers of the same medical school. We have obtained 232 responses from the medical students and 57 teachers answered the questionnaire.

Students indicated that 72% of the teachers do not always ask for patient consent to the student's presence, whereas 89% of the teachers stated the opposite. 77% of the students observed patients' discomfort at some time because of their presence and an equal proportion of teachers indicated the same.

This study revealed different perspectives from students and teachers regarding asking patients consent for the student's presence, which might be related to a possible bias in the teacher's sample. Nevertheless, more attention should be given to fulfill patients' right of autonomy.

## Patients' Voice

Irene Durante, Mario Cruz, Jennifer Hincapie, Germán Fajardo  
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Access to information through communication technologies has allowed us to reconsider many aspects of the physician-patient relationships, granting empowering elements to the patient which makes him an active, discursive and decisive agent during his health re-establishing process. The accelerated development of resources, as well as scientific, technical and technological findings, has been such, that in 2016, the World Economic Forum proclaimed this phenomenon as the "Fourth Industrial Revolution". Furthermore, international media agree that digital transformation has changed the usual way of interaction among patients. This has enabled them to compare how different kinds of treatments or medication approaches may or may not work. In other words, sharing their illness experiences. Such digital transformation, followed by a mass media growth, has become the chosen channel to spread illness data through a patient's perspective. It should be noted that, said increment in the exchange of information and data, has not necessarily resulted in better-informed patients, but only in patients with more data. Hence, the need to select the most useful and accurate information as possible. Given the social context in which the healthcare experts are no longer considered as the only valid source of information, concrete measures must be taken to encourage patients, health care providers, organizations or support groups, to use the available technology and raise awareness on this matter.

## Women with Disability: Discrimination and Recognition

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In our complex society, complicated by some elements like family fragmentation, job precariousness, the keystone of the identity becomes the bodily self. The body, however, is fewer and fewer representing the expression of itself, of its own subjectivity, since it has been transformed in an object: almost a container to shape at will, following the rules of beauty forced by the mass media, expression of an intensified recognition quest.

Identity is not once and for all a guaranteed essence and nobody can define itself on its own. Identity is an effect of the relationship, of the exposure to the other. It is in the dialectical exchange between subjectivity and objectivity that the experience of the self takes place. The self, which is unable to realize a self-establishment, asks continuously to be recognized by the other. Nowadays, the exposure to the other one has changed: you cannot mirror yourself in a trusted person, but it is more normal to compare yourself with an abstract and impersonal ideal proposed in a suggestive and subliminal insinuating way by the mass media.

Accordingly, it raises the need for shaping and remodeling our own bodies: a necessity to confirm the control on ourselves, while it has become difficult changing the world, that is translated in the increasingly large use of piercing and tattoos, until reaching the performances of the body art.

In this climate of uncertainty, how is the disabled women perceived?

## Pregnancy with Colon Carcinoma in Medical, Bioethics and Clinical Ethics Perspectives

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**Background:** The number of cancer patients in Indonesia reaches 6% of the population. The incidence of colorectal cancer in women in Indonesia ranks third and cases of colorectal cancer in pregnant women are very rare.

**Observation:** A case report, 32-year-old woman, second gravid, 32 weeks gestational age with an estimated fetal weight of 1800 grams, with colorectal cancer. The main complaint is abdominal pain accompanied by impaired defecation.

**Conclusion:** This case is a risky pregnancy because of progressive pain caused by colon cancer. Medically, treatment of colon cancer can be treated with surgery or chemotherapy, but this is contraindicated in pregnancy. Termination of pregnancy is an option, but the fetus is still in a premature state while pregnancy is expected. In the bioethics perspective, the ethical dilemma is the beneficence, non-maleficence and justice against the patient's autonomy, where termination to improve the quality of life of the patient is contrary to the patient's request to continue the pregnancy. Likewise, clinical ethics (The Four Box) dilemma is medical indication and quality of life against patients' preference. Ethicomedicolegal results are the termination of pregnancy followed by surgery and chemotherapy after informed consent is given.

## Beyond Borders: Telemedicine as a Viable Treatment for Chronic HIV Therapy in Rural India

Shafreen Fatimah  
Yale University, USA

In pursuit of sustainable healthcare systems, telemedicine has been explored for its potential to facilitate major efficiencies in treating acute infections, especially for people living with HIV (PLWH). Yet, few bioethical inquiries address an increasingly important dimension of telemedicine as a provider of long-term treatment: telemedicine as a mode of healthcare delivery in underserved communities. While most studies show high acceptability of telemedicine services among PLWH, the recurring themes in existing evaluations of telemedicine are highly Western or development-centric. This paper thus centers research on the implementation of telemedicine services for PLWH in India, as a bridge between the well-equipped pockets of healthcare systems in urban regions and underserved rural communities. By capitalizing on India's existing disparity in HIV treatment and rapid technological advancement, telemedicine can ideally connect providers to an underserved population. Drawing from secondary sources of journals, conferences and interviews, the paper attempts to utilize bioethical frameworks to recognize the increasing integration of telemedicine in the Indian healthcare system by evaluating the need for telemedicine in the first place. In doing so, the tension between this need for telemedicine and the potential challenges of implementing such a healthcare system is explored and reconciled.

## What Could Possibly Go Wrong? Sociologically Informed Skepticism in the Face of CRISPR

Danielle Ferguson  
Western New England School of Law, USA

As CRISPR technology continues to progress and its availability increases as cost decreases, the conversation surrounding the ethical (moral) considerations of its uses has also progressed. Many scholars discuss these considerations of CRISPR as they apply globally and environmentally. This poster examines the implications for minorities and marginalized communities in the United States compared to marginalized communities globally if eugenic histories were to repeat themselves in modified ways. Specifically, this poster enters the ethical conversation through the lens of historically and sociologically informed skepticism, relying upon the history of eugenics in the United States alongside a history of biases surrounding the black body internationally, to encourage questioning the “what-if” of gene-editing technology. It questions the ways in which we allow technology to be used to further societal notions of what is ‘good’ and acceptable, and by whose definitions of ‘good’ and ‘right’ society abides. Ultimately, this poster will advocate for 1) skeptical analysis of CRISPR’s uses amidst excitement, proposing that the most ethical use of the technology requires a critical analysis of history to ensure history does not repeat itself in progressive forms of harm, and 2) a well-informed bioethical and human rights approach to legal policy surrounding CRISPR’s uses.

## Dismissal for Sickness Absences vs. Rights to Health and Not to Be Discriminated Because of Sex

Francisca Ferrando García  
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The poster will assess the compatibility with the right to health and the prohibition of discrimination, of Art. 52.d) of the Spanish Workers' Statute (SW), according to which workers can be dismissed due to repeated justified absences from work because of illness. The Decision of the Spanish Constitutional Court 118/2019, of October 16, has stated that said provision does not collide with the right to physical integrity of the worker enshrined in art. 15 of the Spanish Constitution (EC), but responds to the legitimate objective of protecting the company's productivity and work efficiency.

However, it could be argued that this dismissal might entail a violation of the worker's rights to health (Art. 43 EC) and to work (Art. 35.1 EC), since, according to art. 6 of ILO Convention 158, the worker's illness is not a valid cause of termination of the contract. Also, Art. 52.d) SW could imply indirect discrimination on the grounds of sex, because it harms women to a greater extent, due to the negative consequences on their health that have their double working time (work and family responsibilities), which negatively affect their activity.

## Communication of the Diagnosis of Spinal Muscular Atrophy to Children and the Principle of Autonomy

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<sup>2</sup>Federal University of Rio Grande do Norte, Brazil

**Introduction:** The relationship of the legal physician-child-responsible trinomial is essential to the moment of communication of a genetic and neurodegenerative disease.

**Objectives:** to analyze the autonomy of this trinomial during the transmission of the diagnosis of spinal muscular atrophy (SMA).

**Methodology:** A questionnaire containing objective questions and the Event Impact Scale - Revised was answered by family members of patients with SMA who experienced the moment of this diagnosis.

**Results:** The sample consisted of 50 family members, 94% of them female. 48% reported sequelae related to the time of diagnosis with direct correlation when the transmission was made by the parents. 22% have a high risk of post-traumatic, relating the feeling of unpreparedness of parents in communicating to their child.

**Conclusions:** Failure to communicate the physician-child-family trinomy brings negative repercussions on the autonomy of those involved, with self-reporting of sequelae, in addition to high risk for post-traumatic stress syndrome.

## Ethical and Bioethical Aspects Related to Female Genital Aesthetics

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Since the end of the last century, we observed that more and more people are looking for body perfection, where the pursuit of beauty imposes no limits. When we talk about the female population, this becomes even more evident. The face or the curves of the waist are not the only protagonists of this story. The vulva has also become the target of searches for beautification, whether by women themselves or by doctors who often do not have the anatomical and scientific basis for performing such procedures. With purely financial goals, they promise to improve self-esteem, without highlighting the possible risks or complications for them.

We cannot allow women to seek information, which is often appealing, on the internet, while Medical Societies do not take a stand with the objective of promoting a consensus on the subject.

We know that we are facing an equation with several variables, namely: cultural values (of the doctor and of women), scientific bases, ethical principles and financial issues. But we also know that the time has come to take a bioethical look at the topic and distinguish the morality in this entire process.



## Advance Directives in Cancer Patients

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**Introduction:** Advance Directives (AD) represent the patient's expression about end-of-life care. Patients who have AD and discuss quality of death, take part in decision making about their care more often and have their choices respected. The diagnosis of cancer seems to favor the establishment of DA and discussions about end-of-life care.

**Methods:** It is a systematic literature review that aims to assess the prevalence of AD among cancer patients and the attitude of patients and physicians across AD in the context of oncology. 10 articles were selected for the analysis in the data source of PubMed and BIREME / LILACS.

**Results:** The prevalence of AD among cancer patients ranged from 88% among Americans at 55% in Canadian. In Europe was low, only 5% cancer patients in one study. Age, level of education, high income, worse Performance Status (PS), prolonged treatment and follow up with a team of palliative care were positive factors related to the development of Advance Directives by cancer patients. The oncologist had the lowest representation among health professionals and family in the formulation process of Advance Directives.

**Conclusion:** The discussion on AD involves, among other things, special attention to the models of physician-patient relationship, particularly the right of choice of patient and respect for their best interest.

## Body Donation to Science: Now in Italy it is Possible

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In Italy, after decades of proposals and requests from universities and researchers, on January 29, 2020 the new law "Rules on the disposition of post mortem body and tissues for study, training and scientific research purposes" was approved. Finally, those who wish can choose to donate their body and tissues for study, scientific research and training purposes, according to certain rules and necessary guarantees. Previously, the lack of regulation in this area, actually blocked the possibility of studying the human body and its anatomy, thus preventing progress in scientific research. Despite the advent of new technologies in the field of virtual reality and simulation, it is necessary to recognize the irreplaceable role of the corpse both in order to improve the quality of the skills of our doctors in the application of the most innovative and advanced surgical techniques, and in the development of new care profiles that will benefit future patients. Therefore, the aim of this work is to highlight how the introduction of this law represents a fundamental tool for Italy to improve training and to stimulate the advancement of research through the study of human corpses.

## Factors Affecting Nurses' Involvement in Establishing Healthcare Policies

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**Background:** Nurses, have the potential capacity to be involved and influence healthcare policy, but in many cases their contribution to policy-making decisions has been unremarkable.

**Purpose:** To develop a model, which would strengthen the involvement of nurses in healthcare decision making policy.

**Methods:** A self-report questionnaire measuring nurses' involvement in determining healthcare policy was distributed amongst 400 nursing students in Israel. The model application was validated on other 118 nursing students who participated in a course: 'Nursing -a socio-political force'.

**Results:** Most students intended to become involved in determining healthcare policy. However, they claimed that their level of knowledge and training in the field was not adequate. The new model, which includes socio-demographic variables, professional and personal characteristics allows a prediction rate of 74.8% who of all nurses will be involved in healthcare decision making policy (p0.02).

Four months after participating in the course, 85% of the students were interested in healthcare policy, 94.9% noted that the role of the nurse is to ensure the realization of health rights among vulnerable groups.

**Conclusion:** Nursing leaders and nursing education programs developers must establish professional and personal resources through health care policy amongst nursing students.

## Suicide in Medical Students: A Local Experience

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University of Pavia, Italy

**Introduction:** Even if awareness on medical students' mental health has risen in recent years, present literature about the topic is pretty scarce, particularly regarding associated risk factors.

**Objective:** To estimate the suicide rate in a sample of medical students, considering nationality.

**Methods:** Cases of accomplished suicides in an Italian University city were collected during a 6 year timespan. Enrolment numbers to medical courses were gathered, as well as residency status and nationality. Suicide rates and odds ratios were calculated and reported.

**Results:** Italian medical students reported a rate of successful suicides of 23.35 cases/100.000/year; in non-Italian medical students, on the other hand, the rate was of 105.15 cases/100.000/year. Odds ratios in comparison to the general population were of 2.85 and 12.82 respectively.

**Conclusions:** Our estimated suicide rates greatly exceeded what was previously reported for the general population. We call for a closer attention on mental health in medical students, particularly for colleagues from abroad, which can have great difficulties in everyday life. The aim should be to develop a safe and strong social network, in order to facilitate relief from exogenous stressors and decrease risk factors.



## Access to Health Care and Social Services for Patients Suffering from Rare Diseases in Spain

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Most rare diseases are complex and chronic involving a high degree of disability and/or dependence. They reduce the quality of life of patients and their families not only in terms of strictly health-related aspects, but also in physic and social areas, affecting family and financial needs, the inclusion in school or work, etc.

This paper outlines the priorities needs and legal responses in an integrated perspective of health and social services. It focuses on the rights to access to health services and medicines as well as the support and care services for dependent people (home-help, tele-home care, day care centers, residential care centers, etc.).

This set of measures, which are managed by the departments (at state, autonomous community or local level) responsible for those areas, is based on a series of laws of a basic nature and inter-sectorial scope, like Spanish Act 16/2003 on Cohesion and Quality of the NHS; Spanish Act 39/2006 on the Promotion of Personal Autonomy and Care for Dependent Persons; Act 51/2003, on Equal Opportunities, Non-discrimination and Universal Accessibility for Disabled People; Spanish General Social Security Act, approved by Royal Legislative Decree No 8/2015, etc.

## Promotion of Subjective Well-Being in Older People with Dementia: Reminiscence Therapy

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This study aims to explore the effects of reminiscence, in the promotion of subjective well-being in elderly people with dementia living in nursing homes. Therefore, it was implemented a reminiscence program, resulting in a final biographical book offered to each participant.

Sample consists of 6 elderly people aged between 84 to 94 years old, with mild to moderate dementia stage who were institutionalized either in nursing homes and in a medium-term continuous care and rehabilitation unit.

The Clinical Dementia Rating Assessment Protocol was used to assess the dementia stage and to determine the inclusion or exclusion of participants in the intervention. In order to analyze the results, Subjective Well-Being Assessment Scale (involves the Satisfaction with Life and the Positive and Negative Affects) was used as a pre and post test.

Results suggest that reminiscence has an effect on the subjective well-being of people with dementia. Furthermore, the results of life satisfaction scale reveal statistically significant differences between pre and post test, suggesting that reminiscence may influence life satisfaction. These data allow to recognize reminiscence as a non-pharmacological intervention with great potential to be adopted in gerontological contexts for people with palliative needs, aiming to promote their subjective well-being.

## Medical Education: Patients' Perspectives on Clinical Training and Informed Consent

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There are complex ethical dilemmas inherent to the teaching of medicine, particularly relating clinical practice involving actual patients - how can we fulfil medical students' training needs while still respecting patients' fundamental rights to autonomy and privacy?

We aimed to assess patients' perspectives regarding medical students' involvement in their medical care and to evaluate the need to implement further measures to regulate student-patient interactions. An interview-like questionnaire was applied to patients waiting for a consult/admitted to three departments: General Surgery, Obstetrics/Gynecology, and Infectious Diseases. Patients' responses according to different variables were compared using the Chi-Square Test and Independent Sample T-Test.

77% of interviewed patients reported previous experiences with medical students, but only 59% stated that they were asked for consent for their participation. Gynecology/Obstetrics patients reported the smallest rates of these practices and were also the ones most bothered by students' presence, stating they would refuse students' participation in the future.

The study shows that there's a need to pay closer attention to fulfilling of patients' fundamental rights. Patients are an essential part of clinical training and they might be less accepting of medical students' participation in the future due to an inadequate behavior by both students and their teachers.

## Quality of Life Assessment through the SF 36 Questionnaire in Elderly

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The study's intention was to analyze comparatively Life Quality between the senior citizens who participate in the Public Physical Activity Programs in Nisa - Portugal (Program Activ Senior) and Florianópolis - Brazil (Program Floripa Ativa).

Besides, it compares the intervention models and the benefits for ageing in an active way, considering the respect for the rights, autonomy, differences, limitations of individuals, preserving the physical and mental health in conditions of freedom and dignity.

**Methodology:** Using the SF36 (Medical Outcomes Study 36-Item Short - Form Health Survey), valuated and adapted for both countries, a transversal descriptive study was carried out from October to December 2011, including 258 senior citizens (129 Portuguese subjects and 129 Brazilians), both genders, whose ages were equal or more than 60 years old.

**Results:** The highest score for both cities were obtained in the Mental Component: Social Function (83,8), although the worst score appeared was Vitality (69,1).

**Conclusion:** The results suggest that collective health strategies, adopted in both countries through their Programs, establish social bonds, health gains and benefits for active ageing, representing a high and positive impact within the societies, since they maintain the elderly physically active.

## Family Planning under Brazilian Law: Advances or Limits?

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Arlindo Lopes de Almeida Neto, Paula Galvão Duarte,  
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**Introduction:** The creation of Law No. 9263/96, which governs family planning in Brazil, regulates in article 10 the voluntary sterilization as a guaranteed right under the tutelage of the State. According to the document, surgical sterilization is permitted for individuals with full civil capacity and over twenty-five years of age or with two living children, provided there is the express consent of both spouses. Currently, however, there is an important discussion about the ethical foundation and the constitutionality of such law.

**Objective:** To identify changes in the scope of voluntary sterilization in Brazil after this law and State's role as a promoter and protector of this right.

**Methods:** A survey was conducted in databases as JUSBRASIL, SCIELO, PUBMED e BVSM, guided by specifiers: "Sterilization, Reproductive", "Bioethics", "Brazil" and "Family Planning", followed by analysis of the selected articles.

**Results:** The analyzed cases evidenced the increase in the surgical sterilizations over the years, as well as the recurring decision by the State in favor of those that meet the legal requirements. It is considered that Brazilian law has provided access to the population that seeks this method, however there is a deficiency in public policies directed to the control of contraception.

## Killing the Look Out: The Unjustifiable Death Penalty for Those Not Culpable

Megan Hoberg  
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The question of whether the death penalty is ethical is debated among legal, medical, and philosophy scholars. However, these scholars have not adequately addressed the ethical issues that arise when an individual who has not committed a murder is held liable for such and subsequently killed by the state. This paper presents an ethical analysis of culpability, death penalty, and what role the legal and medical communities ought to play in this discussion. Specifically, this paper examines the abuse of the death penalty under felony murder rules, to demonstrate how it is inappropriate to hold those who did not kill liable for murder. This discussion brings to light the misunderstood 'sanctity for human life' and deterrence arguments that are incorrectly used as a defense for the felony murder rule and capital punishment. I argue both the felony murder rule and death penalty are unethical with an emphasis on fighting against the perpetuation of violent racism, as evident by the enforcement of aggressive sentencing for People of Color. This work sheds new light on the neglected study of those who received the death penalty under the felony murder rule.

## Workshop on Clinical Ethics Using "Bioethics Core Curriculum, Section 2: Study Material " by UNESCO

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**Introduction:** The Japan Unit of the International Network of the UNESCO Chair in Bioethics (Haifa) is currently translating "BIOETHICS CORE CURRICULUM, Section 2: Study material" into Japanese. Cases from this book were discussed at interprofessional workshops on clinical ethics to explore ways to best use this material.

**Methods:** Clinical ethics workshops were held on May 25th and October 14th, 2019. A questionnaire developed through a preliminary survey was administered.

**Results:** We received responses from 31 people. Twenty-eight (90.3%) found that the case study was useful and 27 (87.1%) said they would use it when published. Thirty (90.3%) mentioned its usefulness in practicing Jonsens's "Four Quadrants" approach. Though the case study was regarded as useful, eleven people (35.5%) thought that there was not enough information in the cases for thorough discussion. Some thought that the cases did not fit the situations in Japan.

**Conclusion:** "Japanese version" is expected to be released. Many regard it as useful in discussing ethical issues and practicing the "Four Quadrant" approach. Some found the lack of information in the cases. However, lack of information could leave room for further discussion. The ways for Japanese to study the cases to broaden their horizons needs to be explored.

## Can the Carpenter Blame Their Tools: Who Holds Responsibility in Robotic Surgery?

Jacob Howard  
University of Central Florida, USA

Robotic surgery consists of some of the most cutting-edge technology within the operating theater. With this great power comes great responsibility, and the way this responsibility is apportioned changes as more individuals are involved in the shaping and implementation of technology within robotic surgery. Legally in most jurisdictions, the operating physician or the hospital bears the brunt of the blame when errors occur within robotic surgery, but this appears to be unfair at second glance. Surgical robot manufacturers, software engineers, educators/training programs, and those who design the implementation of technology within the operating theater all affect the outcome of robotic surgeries. Literature across the field of robotic surgery has shown that behaviors from these groups can have major downstream effects on error within robotic surgery. The purpose of this exploration of robotic surgery is to highlight just how much groups that may not be commonly held responsible actually contribute to surgical outcomes and how these conflicts with intuitions to continue placing responsibility unevenly on the practicing surgeons and their surgical teams involved despite the changing landscape of the operating room in robotic surgery.

## Teaching Clinical Ethics with Online Team-Based Learning

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Excellent clinical ethical teaching is the application of science into clinical care. When a medical student encounters ethical issues in the clinical cases, it is challenging to teach clinical ethic systematically in the actual clinical setting. Another big problem is that during medical students' clerkship, they are scattered in various hospitals, and it is difficult to bring them together for the ethics class. We developed an online Team-Based Learning (C-TBL) course to try to resolve the current problems.

There were 54 5th years medical students in 4 teaching hospitals in Taiwan who participated in the curriculum. The C-TBL course including the procedures of individual readiness assurance test (IRAT), group readiness assurance test (GRAT) and group case studies with faculty facilitation. Our research discovers that the convenience of online learning was highly approved. The development of using Google form to perform GRAT test also got good responses from students. As a result, even if we found an effective way to deliver IRAT and GRAT, online discussion was still an intricate part that students are unfamiliar with and have low acceptance.

## Is the Principle of Autonomy the First Principle of Medical Ethics

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**Background:** In 1985, Beauchamp and Childress put forward four basic bioethics principles for medical ethics judgment: respect for autonomy, nonmaleficence, beneficence, and justice.

These four basic principles of bioethics are sometimes consistent with real medical situations. However, they are often in conflict with each other. Hence which should be the first principle to follow?

**Methods & Discussion:** The medical decision is not only about medical treatment but also an ethical judgment. In clinical medicine, we have clinical practice guidelines. When making ethical judgments, can we also have a guideline to help us when we are at a loss?

The main target of medical treatment is to treat the disease of the patient, not the disease itself. Therefore, the essence of medicine is healing, not curing. Healing focuses on the patient's real-life condition. Consequently, they have the right to decide what is important to them. This article aims to prove that autonomy should be the first principle by two orientations. The first orientation is back to the essence of medical treatment, and the second orientation is the perspective of Existentialism.

**Conclusion:** Existentialism care about "each" patient's being. That is the core value of medical treatment we called "holistic health care." Only when autonomy is based on Existentialism can it truly practice the value of medical ethics. At that time, the patient is treated as a whole existence, not a disease's carrier. And the difference is awareness.

## Speak No Bias, Hear No Patient, See No Color: The Mis-Categorization of Racism in Healthcare

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Implicit racial bias is improperly used as an interchangeable term for racism. Equating the two leads to a lack of accountability and denial of the systematized problem that is apparent in many facets of American culture, systems, and customs. While the definition of implicit racial bias is meant to be niche in the actions it considers, there are many concerns. The causation of the actions conducted under the guise of implicit racial bias, represents the indoctrination of a majority within the U.S to adhere to ideals presented in efforts to perpetuate superiority power structures. This poster examines how the lineage of such beliefs are disregarded by bioethicists and healthcare professionals, to exhumate fault within the individual, but not within the profession as whole. The relabeling of terms makes the assumption that implicit bias is beyond control, while also generalizing that everyone acquires biases solely on an individualistic basis with no outside influences. This uncontrollable trait absolves violators of responsibility, leading to few consequences being imposed in order to mitigate the damaging behavior. Diluting the notion of "racism" to "bias," leaves such differentiations vulnerable to be used to disregard systematic responsibility, and to continuously perpetuate racist ideologies. The various factors of the terms must be examined in depth by a diverse institution, in attempt to produce a better understanding to lessen the damaging impact mis-categorizations have.

## Does Consent Correlate with Adolescence? Autonomy to Initiate Transgender Reassignment Treatment

Miguel Ignacio Herrero  
Yale University, USA

With the reconceptualization of the term transgender from 'gender disorder' to 'gender dysphoria' by the Diagnostic and Statistical Manual of Mental Disorders (DSM), and the appearance of medical guidelines to gender reassignment treatments, a bunch of ethical issues have arisen. This paper reviews the main treatment processes and breaks down the concept of autonomy in order to determine if minors should have the decision-making freedom to consent to treatment for themselves. The role of secondary effects from hormones in addition to the potential changing of minds of transgender individuals in adulthood will be explored when considering the granting of complete autonomy to minors in this decision-making process. The psychiatrist, who plays an important role in applying the "mature minor" approach, has a responsibility of establishing a stable environment for the minor, preparing the individual rather than giving them full authority over their autonomy. In other words, the psychiatrist should focus upon the relationship between the minor and other surrounding stakeholders, such as family and friends, rather than allowing the minor to have full control over the choice in regards to gender reassignment treatments.

## Loneliness and the Effect on Health Outcomes and Quality of Life in Palliative Care Patients: A Scoping Review

Fabio Ikedo  
University of Porto, Portugal

**Background:** Loneliness has emerged as 'public health epidemic', with impact on health and quality of life (HQOL) and can affect those under palliative care (PC). A higher prevalence of loneliness among terminal patients has been reported. This scoping review seeks to present an overview of the literature on loneliness and HQOL in PC patients.

**Methods:** This review followed the 5 scoping review stages outlined by Arksey and O'Malley, using a 5-year review period.

**Results:** The search yielded 244 articles through two databases (Pubmed and Scopus). After the screening based on title and abstract, all articles were excluded, except 3 papers. Full text analysis excluded 2 articles. Only one article was included in the scoping review, where loneliness was evaluated in terminal stage cancer patients. Loneliness was significantly higher in patients who had no visitors, in those who complained about insufficient social support, and in those with no one with whom to share their emotional problems.

**Conclusion:** Although loneliness has been a prominent focus in recent studies on physical health, loneliness in PC patients has not received a special attention with regards to the effect of loneliness on HQOL. There is an unmet need of loneliness and HQOL studies in PC.

## "Gestational Determinism" in the Transnational Surrogacy Industry: Exploring the Implications of Epigenetic Research on Industry Practices

Sasha Isaac  
Australia

In the "politics of fetal harm", mothers are the primary vectors of risk (Daniels 1997, 579). This view is exemplified in the vast corpus of epigenetic studies framing women as the sole arbitrators of fetal health outcomes, continuing a long-standing tradition burdening women with primary responsibility over the fate of future generations (Sharp, Lawlor, and Richardson 2015). In the politics of transnational surrogacy, however, the power of the maternal body is necessarily limited. To maintain surrogacy's appeal, clinics must downplay the fetus-gestator relationship in order to privilege the genetic & social link between intended parents and their future child. With India's recent ban casting fresh doubt upon the ethics of the practice, it bears to consider what impact this ever-growing body of literature on what I dub "gestational determinism" has on the debate about transnational surrogacy. In this paper, I argue that the longstanding tension between capitalist interest and scientific discourse presents a wholly unique problem for surrogacy clinics: To reconcile these two competing accounts of maternal influence, clinics must now choose between (1) downplaying the power of the gestational environment—else risk losing the appeal of their service to hopeful couples—and (2) acknowledging the newfound power their surrogates now possess—else risk opposing scientific consensus. In either scenario, the dynamics of the commercial surrogacy industry will be profoundly changed.

## Patients' Right to Different Knowledge Areas: Patient Ombudsmen's Perspective

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**Background:** Patients' right to know (PRtK) about their health and care is a fundamental human right. For supporting this right, patient ombudsmen (PO) have an important role, but evidence of this support is limited.

**Aim:** To analyze what knowledge areas emerge in relation to the PRtK when patients contact PO.

**Methods:** The sample was PO reports, describing contacts between patients and PO, in one university hospital district in Finland in 2019 (N=2010). In the analysis, deductive analysis matrix of dimensions of empowering knowledge was used (bio-physiological, cognitive, functional, experiential, ethical, social, and financial).

**Results:** There were 130 (n=) PRtK-related reports. These were related to adults (≥18-year-olds, 95%), mostly to patients themselves (62%) or their significant others (36%). Most commonly, the reports were in the bio-physiological knowledge area (68%, e.g., inadequate knowledge on treatment), followed by cognitive (33%, e.g., difficulties to understand information), social (28%, e.g., unmet needs of significant others) and ethical knowledge (24%, e.g., confidentiality issues). Financial (6%), functional (5%), and experiential (0%) areas were rare.

**Discussion:** Findings suggest further need to support the PRtK, main issues being in the bio-physiological knowledge area. In the support, PO and health care professionals earn evaluation of outcomes of different support solutions.

## The Concept of Duty in a Pandemic Covid-19 According to the Kantian Approach

Eleni Karamatziani<sup>1</sup>, Andriana Zisimatou<sup>1</sup>  
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Pandemic is an important issue and always up to date, as it raises thoughts, debates and great controversy about the ability of a person to choose the way and the time frame of death. In this presentation I will try to approach this issue in the light of the Kantian moral tradition and I will examine how in the case of pandemic man tries to escape from a difficult situation he is going through using himself only as a means to maintain a bearable status till the end of his life. At the same time, I will focus gradually. How should a doctor treat these conditions? What principles of law should be applied? Each case should be treated differently and, in the end, what are the criteria for admission to the Intensive Care Unit (ICU) and the use of respirators? Who determines who will live and who will end up?

However, man is not an irrational being, which would make him a thing, used only as a means, but has in all his actions to always be considered as an end in himself. I would claim, according to Kant, that in this case he cannot use mankind to his benefit or allow to wear him or cause him to die. I will conclude that in the case of such important issues as pandemic, the idea of freedom is maintained, which is subject to the autonomy of the will.



## Issues in Conducting HIV Clinical Trials in India

Pearl Kosala Raman  
YRG CARE Medical Centre, India

Clinical research which includes clinical trials, is the foundation of evidence-based medicine and is the most reliable method of producing reliable data. Over the last decade, India has been one of the preferred destinations for clinical research. One of the major ethical issues which has emerged is of compensation to research participants for clinical trial-related injury or death.

Clinical trials funded by International Government sponsors do not compensate nor take the accountability for Clinical trial related Injury or Death, and it is the sole responsibility of the Investigator in aiding to the participant's compensation.

The Pharmaceutical driven clinical trials take up the responsibility in compensating participants who volunteer for drug related clinical trials. Indian guidelines laid out by DCGI has come up with regulations regarding compensation for research participants.

The sponsors should be aware of differences in the Indian GCP version, including the Indian compensation for participation, as well as the roles and responsibilities of foreign sponsors following ICH-GCP, conducting clinical trials in India.

The sponsors responsibility for compensation for an injury related to the study drug would depend on the description of the 'study' specified in the Study Protocol and the Informed Consent Form.

## The Use of Human Cells, Tissues and Organs in Medicine: A European Legal Perspective

Beata Kozielwicz  
University of Warsaw, Poland

The progressive development of biomedical sciences enabling the scientific use of cells, tissues and organs of the human body or their elements is a challenge for modern legal sciences. In my presentation I will discuss the issue of the possibility of using cells, tissues and organs of the human body in medicine based on legislation of the European Union (EU) and selected EU Member States.

The concept of human body is considered to be difficult to define and requires far-reaching caution when it comes to regulating its status. The issue of human body products has also become specified in derivative provisions of EU law, e.g. Directive 2002/98 / EC, Directive 2004/23 / EC. What is more, the legal nature of the possibility of using human cells in biotechnology has already been raised in the jurisprudence of the Court of Justice of the European Union (e.g. judgment of the Court of Justice of the European Union of 18 December 2014 in case C-364/13 International Stem Cell Corporation / Comptroller General of Patents).

The problem of liability for damages caused by medical errors, e.g. by incorrect implantation of bioimplants or incorrect cord blood supply remains also particularly relevant and will as well be mentioned during my poster presentation.

## Brazilian Legislation on Ethics in Human Research and Its Applicability in Ethics Committee

Marcelo Lima, Silvana Molina Lima, Lucileia Gothardi,  
Trajano Sardenberg  
São Paulo State University (Unesp), Brazil

Research involving human subjects had important regulation by the National Research Ethics Commission (CONEP) with Resolution 196/96, which was later edited by Resolution 466/12. Through these resolutions was created the Research Ethics Committees (CEPs), collegiate bodies with the purpose of approving projects with research in human beings. More recently, new resolutions were issued as 510/16, which dealt with applicable standards for research in the Humanities and Social Sciences, 563/17 that dealt with the right of research participant with ultra-rare diseases, and 580/2018, which deals with strategic research for The Public Health System. By issuing the resolutions cited, it was possible to delineate a better performance and evaluation of projects submitted to CEP reaching the objectives of analysis, adequacy and approval in order to ensure an ethical opinion with clarity, legal basis and basis on specific legislation, necessary for the credibility and reliability of the Brazilian ethics system, being fully applied the edited legislation as recommended by the national research body. It is concluded that with the set of rules issued by CONEP allowed greater sustainability to the opinions issued by the collegiate, ensuring the guarantees of the institution, performance of researchers and especially preserving the right of research participants.

## Advanced Age Women: Insufficient Pensions and Need for Care

María del Carmen López Aniorte  
University of Murcia, Spain

Real and effective equality between both sexes in terms of income is far from being achieved. This is evidenced by the considerable gender gap in wages and pensions, estimated at the level of the European Union (year 2019), respectively, at 16% and 35%. The cause of this gap lies in the assumption, by women, of the role of caregivers (they perform 76.2% of all unpaid care work worldwide), which has serious effects on their occupational health, expels them from work and leads them to exercise the conciliation rights.

The gender gap in the retirement pension manifests itself in a greater difficulty for women to meet the requirements for access to said pension and in that female pensions are lower. This circumstance puts them at risk of exclusion and poverty at an advanced age. In this way, they will be forced to face the cost of the greatest care required during this vital stage, with lower incomes than men and for a longer time (their life expectancy is higher). Such an unfair situation, suffered by many elderly women in a state of vulnerability, deserves to be a priority object of attention in any reform contemplated in the different Social Security systems.



### Differences in Lifestyle among Polish and Foreign Students Studying in Poland

Michał Machul, Anna Obuchowska, Paulina Mazurek, Piotr Pawłowski, Daria Makuch, Adrianna Bartoszek, Agnieszka Chrzan-Rodak, Monika Bieniak, Jadwiga Bąk, Justyna Chałdaś-Majdańska, Katarzyna Karska, Beata Dobrowolska  
Medical University of Lublin, Poland

**Background:** Educational migration across the world challenges healthcare professionals with the issues relating to cultural adaptation among foreign students, expressed e.g. in lifestyle changes. The aim of the study was to analyze differences in lifestyle of Polish and foreign students studying in Poland.

**Methods:** Cross-sectional study on a sample of 444 students, 231 foreign and 213 Polish, studying in Poland. Three research tools were used: Fantastic Lifestyle Questionnaire (FLQ), Perceived Stress Scale (PSS-10) and Satisfaction with Life Scale (SWLS) as well as a short form for sociodemographic data. The study protocol was approved by the Ethical Commission (No. KE-0254/24/2018).

**Results:** The average age of surveyed students was 21.9 (SD=3.98). Polish students more often assessed their health condition as good (60.1%) than foreign students (50.2%). Student's life changed their lifestyle (86%), more often in case of foreign students (90.9%) than Polish (80.7%). Foreign students obtained worse global results in FLQ than Polish (p<0.001). Students from Europe (including Polish) obtained better global results in FLQ than American and Asian ones (p<0.001). The level of stress intensity was higher among American students than others (p<0.001).

**Conclusions:** Studying in a different country affects students health behaviors more than in case of native students.

### Bioethics, Euthanasia and Assisted Suicide: Normative Comparison, Regulation and Ethical Arguments in Several American and European States

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<sup>2</sup>Federal University of Uberlândia, Brazil

Terminality of human life has always raised difficult questions in theory and in practice. There are several countries that have legalized euthanasia or assisted suicide. Others have legal provisions that decriminalize these practices. In Brazil the clinical anticipation of death is still seen as a legal and ethical problem. It can be regarded as illegal on the Criminal Code. In this work the aim was to expose, analyze and discuss some essential aspects of voluntary euthanasia and medically assisted suicide comparing legal permission or non-criminalization in states of European and American continents. A documental study on euthanasia and assisted suicide in international and domestic regulations was also carried out in the countries studied. It was concluded that there are common aspects and particular aspects in each studied country and their legislations on the subject, including interpretation of human rights and bioethical principles, also common and particular points in each one. In Brazil this suggests we think about the presence or absence of these aspects, and how religious, legal and medical views support or reject the legalization of medical care to the anticipation of death.

### Organ Donation in Corpses Undergoing Forensic Autopsies: The Italian Legislation and Possible Room for Further Improvement

Martino Maesani<sup>1</sup>, Umberto Rosini<sup>1</sup>, Carmen Scalise<sup>1</sup>, Matteo Antonio Sacco<sup>1</sup>, Fabrizio Cordasco<sup>1</sup>, Angelica Zibetti<sup>1</sup>, Francesco Maria Galassi<sup>2</sup>, Elena Varotto<sup>2</sup>, Santo Gratterer<sup>1</sup>, Pietrantonio Ricci<sup>1</sup>, Isabella Aquila<sup>1</sup>  
<sup>1</sup>Magna Graecia" University of Catanzaro, Italy  
<sup>2</sup>Flinders University, Australia

In this work the aim is to provide a brief summary on how organ donation is managed in Italy, starting from the laws regulating this field, the first dating back to 1957; it will subsequently be explained how the Italian legal and health system have managed to combine this particular possibility with the need of the forensic pathologist to ascertain the exact cause of death; finally an attempt will be made to hypothesize possible modifications to the current procedure in order to facilitate organ donation while preserving the possibility for the investigating authority to find the exact cause of death. It will be shown how the rapid progression of science forced legislation to adapt in order to minimize the loss of potential organ donors, from law number 235/1957 to the ever evolving regulation present days. The second point will be illustrated based on the jointly elaborated operative guidelines "Procurement Procure", from the North Italian transplant program in collaboration with the Istituto Superiore di Sanità and the Regional Health service of Lombardy. The last point will be an attempt to improve on said guidelines via modification that will make those procedures more widely applicable.

### Ethical Differences between Various Forms of Physician Participation in Capital Punishment

Mihnea Theodore Marghitu  
University of Minnesota - Twin Cities, Romania

Despite the AMA's statement in the Code of Medical Ethics banning all forms of physician participation in capital punishment, surveys have shown that many physicians are willing to be part of such acts, and some of them actually do so. These surveys have also indicated that a physician's willingness to participate is influenced by what they would be expected to perform during the execution. Indeed, more physicians were willing to perform "minor" tasks such as pronouncing the prisoner dead than injecting the lethal drugs, but the literature has not explored whether or not there is an ethical difference between these acts. This paper presents an ethical comparison of the various forms of participation in capital punishment using a "killing versus letting die" thought experiment, often present in discussions surrounding passive and active euthanasia. More specifically, this essay establishes a parallel between active euthanasia and the "active" forms of participation in capital punishment, as well as between passive euthanasia and the "passive" forms of participation in executions. This paper then translates arguments that establish a difference between passive and active euthanasia in order to test their validity in the case of capital punishment.

## Organizational Ethics in a Health Care Institution: The Experience of CISSS Chaudière-Appalaches

Ana Marin, Pierre-Maurice Ferland  
CISSS de Chaudière-Appalaches, Canada

In Quebec province the organizational ethics is present in public institutions for two decades. The health and social care system, even though it is public, is an exception. Privileged place for bioethics, medical ethics and clinical ethics, the health and social care field try now, since the last big reform in 2015, to integrate the organizational ethics. This reform created big structures that integrate many different missions (hospital care, readaptation, child protection etc.) with different cultures and values. In this context, the issues for organizational ethics are important. This presentation has as goal to expose the experience of the CISSS-CA (Centre Intégrée de Santé et Services Sociaux de Chaudière-Appalaches) in the integration of organizational ethics between 2015 and 2019.

## Bioethical Issues in Organ Transplantation

Rositsa Markova, Vidin Kirkov, Mila Kirkova, Simeon Simeonov  
Medical University-Sofia, Bulgaria

Clinical organ transplantation has been recognized as one of the most gripping medical advances of the century as it provides a way of giving the gift of life to patients with terminal failure of vital organs, which requires the participation of other fellow human beings and of society by donating organs from deceased or living individuals. These events have raised many ethical, moral and societal issues regarding supply, the methods of organ allocation, the use of living donors as volunteers including minors. It has also led to the practice of organ sale by entrepreneurs for financial gains in some parts the world through exploitation of the poor, for the benefit of the wealthy.

This review deals with the ethical and moral issues generated by the current advances in organ transplantation, the problem of organ supply versus organ demand and the appropriate allocation of available organs. It deals with the risks and benefits of organ donation from living donors, the appropriate and acceptable methods to increase organ donation from the deceased through the adoption of the principle of 'presumed consent', the right methods of providing acceptable appreciation and compensation for the family of the deceased as well as volunteer and altruistic donors, and the duties and responsibilities of the medical profession and society to help fellow humans.

## "Here is (not) my Home!" Considerations about Institutionalization and Identity of Elderly Person

Filipa D. Marques<sup>1,2</sup>, Liliana Pereira<sup>1,2</sup>  
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The institutionalization process assumes a series of challenges for the elderly person. This study explores the process of institutionalization of the elderly person and aim to understand the influence of this process in their identity. This exploratory and qualitative study has a phenomenological design applied to a sample of five elderly women (aged 72 to 93 years old) living in a Nursing Home (for over a year) in Oport district, Portugal. The main results suggest that institutionalization contributes to modify and/or loss of identity that leads to the depressive symptomatology, mainly due to: (i) the loss of house space and particular daily dynamics and routines; (ii) difficulties related with institutionalization, and (iii) conditioning the preservation of will and freedom in decision-making of the institutional standards and rules. These aspects seem to compromise the psychological well-being of the participants, reflecting a predominantly negative perception, guided by institutionalization feelings as nostalgia, sadness, alienation and apathy to institutional life.

## Bioethics in Graduation: The Importance of Deliberation on Principles and the Big Issues

Luiz Martins<sup>1</sup>, Carla Terra<sup>2</sup>  
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<sup>2</sup>University Presidente Antonio Carlos, Brazil

The term Bioethics was created and put into circulation in 1971 as a discipline that should allow the passage to a better quality of life. Its fundamental principles guide the practices, decisions, procedures and discussions related to health care. The goal is to warn about the importance of discussing major issues in undergraduate studies. A literature review was conducted using books and articles published from 2000 to 2015, with the theme's "bioethics", "big questions" and "bioethics in undergraduate". Bioethics promotes philosophical reflection on the moral, social and legal problems posed by the development of civilization. The ethical problems generated by advances in the biological and medical sciences reached their apex when the power of man to interfere in the processes of birth and death began to spread widely. Therefore, major issues such as cloning, euthanasia, medical ethics, stem cells, abortion and informed consent should be widely discussed in academic education in order to provide students with better knowledge and skill in the performance of their future professions. It is essential to promote deliberation and foster the teaching of bioethics in the various undergraduate degrees.

## Opiophobia as a Barrier in Therapy of Pain: What Do Future Medical Doctors Think About?

Branislava Medic, Katarina Savic Vujovic, Nevena Divac, Sonja Vuckovic, Radan Stojanovic, Dragana Srebro, Milos Basailovic, Milica Prostran  
University of Belgrade, Serbia

Opiophobia represents an irrational fear of using or prescribing opioids. Key barriers to prescribing opioids in medical doctors include addiction potential, abuse or misuse, side effects and fear of review by professional bodies. The consequence is an inadequate pain management.

We aimed to assess knowledge and attitudes of medical students towards the issue of opiophobia in Serbia. A self-completed questionnaire was delivered to 361 out of 548 students of the 3rd year (65,87 %) and 307 out of 504 students of the 6th year (60,91 %).

Most of students stated that they do not know or not sure what a term "opiophobia" represents (3rd year 67.86%, 6th year 55.92%). Although most of our respondents believed that opioids can relieve the strongest possible pain, they pointed out that the risk of abuse of these drugs in our community is conspicuous. The final year's students provided significantly more accurate answers concerning the effects of opioid analgesics (P 0.001). Also, both group of students estimated that patients are greatly feared of certain side effects of opioids such as tolerance and respiratory depression (P 0.05).

It is necessary to improve knowledge and attitudes of our medical students towards the issue of opiophobia.

## Exploring Mental Health Patients' Perceptions and Aspirations in Employment

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**Aims:** To explore mental health in-patient's perceptions and aspirations in employment to produce a lay document on employment.

**Background:** Employment is beneficial, it improves mental health and better social integration. Different interventions exist to support mental health patients into employment. However, patients experience many obstacles, including the characteristics of their condition and stigma.

**Methods:** Literature review, using a search string on PubMed focusing on mental health and employment.

Developed a 17-question questionnaire exploring patients' perceptions and aspirations in employment

Created lay document containing information on benefits of employment, employment rights and accessing employment.

**Results:** 100% of patients interviewed were interested in employment. 90.9% believed employment would improve their mental health and 100% believed it would improve their connection to their community. 100% felt there is a stigma around mental health problems which makes finding employment harder.

**Conclusions:** The barriers mental health patients seeking employment face are varied and complex. Most wish to seek employment, and should be encouraged, as the health benefits are clear. Professionals need to acknowledge individual barriers patients face including different mental health characteristics, ethnicity, gender and personal circumstances and find a way to create a bespoke service tailored to patients' needs in order to secure employment.

## Recognizing Values and Engaging Communities Across Cultures: A Researchers Protocol

Rakhshi Memon

Yale Interdisciplinary Center for Bioethics / University College London UK, UK

Capacity and capability building in Low- and Middle-Income Countries (LaMIC) is high on the global health agenda. Visiting Western researchers are faced with the challenges of conceptualizing bioethical concepts of Respect for Autonomy, Beneficence, Non-maleficence, and Justice in local cultural contexts. Pakistan Institute of Living and Learning (PILL) and University College London (UCL) UK have collaborated to better understand the differences in beliefs, values and norms of local communities. This paper aims to understand how western values are understood by the local indigenous researchers and what are the differences or other important factors to be considered? Group discussion was conducted with local indigenous researchers at PILL. Discussion revealed three common themes; 1) cultural differences (etiquette and code of practice); 2) concept of autonomy and privacy; 3) notion of respect and trust. These findings will inform development of a researcher's culture protocol to raise awareness and to prepare Western researchers when conducting cross cultural research that, in some culture's interconnectedness is valued above individual autonomy; the notion of informed consent may be a collective family decision; shared decision making is based on the doctor/patient relationship that 'doctor knows best' and respect and privacy may have completely different meaning. Although, bioethical principles apply across cultures they need to be contextualized in different cultures.

## Technologies Versus Cognitive Enhancement: Possibilities and Limits

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The advances on technoscience and digital imaging, allowed us to study and to improve our knowledge about brain mechanisms. It was possible to have a better knowledge of the cognitive functions. Consequently, the interest in the technologies, that can improve our brain capacities, started to increase. These new technologies become desirable, because they can lead to advantages in school performance and professional practice with significant social consequences.

Technology brings up possibilities and challenges in different application contexts, though there are limits that must be considered. The increasing use of substances as psychostimulants, for a non-therapeutic aim, became a reality, especially in students at the universities and to improve the performance on certain jobs.

The access to psychostimulants is not yet properly regulated, so it is very common the selling of those products in the internet. Unfortunately, many internet sites, where you can buy those products, do not present side effects and other ethical aspects regarding consumption.

Through a literature review, the authors intend to analyze technological advances, related to cognitive improvement, and to reflect philosophically, ethically and legally about personal and social consequences related to the commercialization and consumption of psychostimulants and neuro technology.

### Assessment of Knowledge Level and Positioning on Health Ethical Prioritization: A Review

Tatiana Menezes Garcia Cordeiro<sup>1</sup>, Rui Nunes<sup>2</sup>, Guilhermina Rego<sup>2</sup>, Ana Claudia Garabeli Cavalli Kluthcovsky<sup>1</sup>, Crisângela Cristin Consul<sup>1</sup>, Eloísa Schroeder Derbli<sup>1</sup>, Flávia Caroline Gonçalves da Silva<sup>1</sup>, Jackeline Raatz de Oliveira<sup>1</sup>, Lais Cristina Zinser Spinassi<sup>1</sup>, Laryssa Kulesza Walter<sup>1</sup>, Milena Christine Król do Nascimento<sup>1</sup>

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This is a literature review on the subject assessment of knowledge level and positioning of healthcare professionals and managers of the Brazilian Unified Health System (SUS) on Ethical Prioritization in Health (EPH). The databases CAPES, Medline, Web of Knowledge, Scopus, PubMed, Lilacs and SciELO were searched, as well as the CAPES, USP, UFPR, PUC, UNICAMP, UNIFESP, UFRGS, UNB and UFRJ thesis databases, searching for papers or theses published until November 20, 2019. We reviewed 846 articles and 123 theses and none of them had as objective the proposed theme. Research on Health Ethical Prioritization is very important in Brazil. The scarcity of public resources and technical advances in healthcare and pharmacology put in doubt the universality and honesty guaranteed by Brazilian legislation.

### The relevance of an ethics committee in a higher education institution in the health area: The experience of ESS-P.PORTO

Pedro Monteiro<sup>1</sup>, Diana Tavares<sup>1</sup>, Agostinho Cruz<sup>1</sup>, Ana Paula Cabral<sup>1</sup>, Alberto Machado<sup>1</sup>, Henrique Curado<sup>1,3</sup>, Helena Sousa<sup>1</sup>, Isabel Faria<sup>1</sup>, Maria João Gonçalves<sup>1</sup>, Maria Manuela Sousa<sup>1,2</sup>, António Marques<sup>1</sup>, Paula Lopes, Paula Lopes<sup>1,4</sup>, Cristina Prudêncio<sup>1,2</sup>

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Ethics Committees arose as consequence of medical-scientific advances made in an eminent demand to extend morality and ethics to the field of biomedicine, to expand and preserve autonomy and dignity of human beings. The Ethics Committee (EC) of Escola Superior de Saúde (ESS) was born in February 2011. The importance for this unit of P.PORTO in having such a committee, for ethical and not legal imperative, came to be corroborated by law (Decree-Law no. 80/2018).

Analysing the Annual Reports, an increased number of processes submitted over the years, most of them obtaining a favorable final analysis, has been observed. Sessions to promote ethical literacy and raise awareness of current bioethical issues have become a vector for its performance, with increasing adherence. The recent implementation of a computerized platform for submission of processes will improve productivity of EC in terms of the response time. With the emergence of the Pedagogical Clinic of ESS-P.Porto, this EC will also have an important role monitoring activities, this time in the clinical scope. From the perspective of this EC and other stakeholders, the Ethics Committee in the ESS-P.Porto has been shown to contribute to the implementation of an ethical culture in academic and clinical communities.

### Research Ethics Teaching: An Experience from Brazil

Silvana Molina Lima, Marcelo Lima, Trajano Sardenberg, Wilza Spiri, Maria Cristina Pereira Lima  
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The Research Ethics Committee (REC) is a collegiate, multidisciplinary, independent, normative, deliberative and educational body, and should always defend the interests of research participants in their integrity and dignity, contributing to the development of research within of ethical standards. This study aims to report REC's experience in offering research ethics classes involving human subjects to students and researchers at a medical school in the State of Sao Paulo, Brazil. Research ethics classes are offered annually to students and researchers at a medical school in the state of Sao Paulo, Brazil. The content of the classes approaches the themes: concepts of ethics and bioethics, Brazilian resolutions that guide research in human beings in the medical and humanities and social sciences, edited by the National Commission of Research Ethics. The classes are taught in an expository, dialogic and individual and group participation. It can be concluded that the ethics classes offered contribute to the educational role of the REC, providing guidance to researchers related to the concepts of ethics and the applicability of current legislation for research developments in Brazil

### The Refusal of Medical Treatment by Older Adults with Cancer

Laiane Moraes Dias, Mirella Rebello Bezerra  
University of Porto, Portugal

**Background:** One of the principles of good care is that it should be responsive to the patients' wishes and values. Little is known about why older cancer patients decide to refuse treatment.

**Objective:** To search about predictive factors associated with treatment refusal by older cancer patients.

**Methods:** A scoping review based on three databases: Medline, Web of Science and Scopus, using the key concepts: "refusal treatment"; "cancer"; "decision making"; "elderly" or "aged". Only articles written in English or Portuguese from the last five years were included.

**Results:** Of 216 abstracts reviewed, a total of 26 studies were included. Only 02 articles include the elderly patients exclusively but the vast majority of the studies demonstrated elderly as a major refusal factor. Most studies focused on breast and head and neck cancer treatment decisions and used a quantitative design. Important factors for refusal cancer treatment included unmarried status, nonwhite race, to have government insurance, advanced cancer (stage III or IV), Charlson Comorbidity Index =2 and fear of side effects.

**Conclusion:** Some socio-demographic and clinical variables are associated with treatment refusal. More studies with elderly are needed. Recognition of these factors may help identify situations where active education and support are helpful to patients accept optimal care.



## Ethical Knowledge and Attitudes of Academic Community of Microbiology at National Autonomous University of Honduras (UNAH)

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The Educational Model at UNAH proposes ethics and bioethics as an integrated axis, to form and strengthen citizen values among their academic community. The research aim was to identify the moral, ethical, and bioethical knowledge and practices of students from different academic levels, graduates, and professors of the School of Microbiology. Data collection was performed through an onsite anonymous unlinked survey. A total of 294 questionnaires were obtained, 214 students, 50 graduates, and 30 professors. Results show that 50% of participants had not received any ethical training during their university studies. More than 90% of the participants indicated that they had some knowledge about ethics, although 50% of them said they did not know about bioethics. There was a positive trend that students in more advanced academic years have a little more knowledge than first-year students. Satisfactory, respondents indicated that they frequently practice the values, virtues, and attitudes that are a priority in personal, social, and professional development. It is necessary a continuous education training program for the Microbiology Academic Community at UNAH, as well as it is to incorporate a course on ethics and bioethics into the new curriculum, and mainstream both axes in all learning spaces.

## What's Wrong with Australian Medical Health Law & the Medical Board of Australia (MBA)?

John Myers

*Clinical Research scholar & Rights advocate, B"H., Australia*

**Background:** The Health Practitioner Regulation National Law Act 2009, like its predecessor the Medical Practice Act 1994, does not take the patient's view into account. Unprofessional conduct & professional misconduct is defined according to (i) the Public's & (ii) the Profession's view. This circumvents the need to consider factual content & context, which is unethical (Myers).

**Method:** The Medical Board of Australia, MBA, investigates every complaint to find fault, not solve problems, they say, "to protect the public". Their funding is by way of membership fees. Internal funding arrangements depend on the complexity & duration of the case, so they contrive more, even a litany of contrived allegations.

**Results:** A review of cases I've been involved in reveals (i) Their modus operandi is to have one admit to a particular course of action that is acceptable, then they construct another and allege that the doctor did not occur in order to make a finding of unprofessional or misconduct. (ii) Bias attends Tribunal & judicial decision in MBA cases. MBA & Tribunal members & judges are not audited.

**Conclusions:** (i) MBA disregards caring doctors, is unethical & self-serving. (ii) A Royal Commission into MBA & judicial bias is warranted.

## Palliative Care is Not Always End of Life Care

John Jeba Raj Muthiah Raj, Reshmitha Vijayakumar  
UK

Into the World of Bioethics can never escape the prime word "Palliation". Palliation necessitates the need of the emotion of 'The End' as the large world presumes. A thought which has to be taken out, detailed into actions and ensuring prompt delivery in the appropriate care setting. A point of note is that palliative care exceeds all limitations of age and sex and will inculcate the clinical background of the individual and the clinical condition to which it is applied and the ethical concerns of the involvement of the families in such decisions play an important part. Palliative end of life care will have to be based on a multi-disciplinary approach with a thin line drawn between life and death, active care and comfort care and catered to the individual appropriately.

A real-life example of a young patient with a rapidly progressive terminal disease. It was felt that the psychological and emotional support to this patient was somewhat lacking as the focus of his clinical care was centered around medical management. Did we give him options for more emotional support/palliative care to handle his diagnosis? did we offer comfort care when we knew things were advancing is the question?

## Current Problems of Application of Medical Law in Russia and in the World

Gulnara Nafikova

*Russia*

Medical law is a rapidly developing branch of Russian law. This industry is inextricably linked to medical science and practice. These relationships are constantly being transformed, modified, becoming increasingly multidimensional and thus clearly demonstrating their viability, autonomy and scientific reasoning.

One of the consequences of such intensive development is the existence of a large number of sources of this branch of law of various kinds. At the same time, an important condition for the proper legal regulation of social relations in the field of health protection - one of the most important areas of social relations in the social and legal State - is certainly the need for systematic regulation of these relations, clarity of the content of legal norms, availability of well-thought-out legal equipment in the preparation of normative acts.

It should be noted that at present the analysis of the provisions of the legal acts in the field of health protection, as well as the materials of judicial practice, reveals significant problems related to the imperfections of the legal regulation of certain aspects of medical activity, as well as the application in practice of certain rules of medical law.



## Conscientious Objection in the Legal Abortion Assistance

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In Brazil performing an abortion is a crime, except when the women's life is at risk, anencephaly and rape resulted pregnancy. Assistance to sexual violence is obligatory and enforced by law. Conscientious objection protects doctors in situations against their principles, denying performing the procedures. The target of the study was to verify the existence and motives of conscientious objection towards victims of sexual violence, to know the structure of attendance of accredited maternity hospitals in Minas Gerais/Brazil. Descriptive and analytical approach including 87 maternity hospitals. It was verified that 68,6% of them don't have suitable infrastructure, 11,4% don't have doctors and 30% were not trained for attendance; 85,7% received patients willing to have a legal abortion with 81,8% without solution; 60,6% of medical staff revealed conscientious objection, for religious motives (31,3%) and ethical (23,8%). It is evident that the system is unprepared for attendance of sexual violence and legal abortion, mainly for conscientious objection, showing the relevance of the study. The result of the research is expected to generate dialogue and debate in bioethics, providing reflection and action about legal abortion. Doctors with conscientious objection might be respected, but there might be alternatives for the assist of the patient.

## Mapping of Research Ethics Committees within Health-Related Higher Education and Research Institutes -Sudan

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**Background:** Sudan has more than 60 medical schools and research institutes that actively conduct human subject research. However, the system for protection of human subjects through adequate research ethics review is yet to be tenable.

**Objectives:** To determine the existence and functionality of Research Ethics Committees (RECs) within academic and research institutes in Sudan.

**Methods:** A tool adapted from the Middle Eastern Research Ethics Training Initiative was used to assess the constitution, members, and review and documentation processes of RECs. A total of 68 institutes were identified as eligible. Telephone interviews with research directorates and/or RECs were conducted.

**Results:** Institutes with established RECS were only 20 out of the 68(29.4%). Eight RECs were registered with the National authority. Collectively the ratio of males to females was 1.7:1 members. Number of members ranged from 5-27, most had between 11 and 15 members. Only 13 (65%) RECs included a non-scientist in their membership. Research ethics training was considered as a criteria for membership in 12 (60%) RECS. Fifty % communicated that their members need training.

**Conclusion:** Though efforts are made to enhance research ethics review, there continues to be an urgent need to address human subject protection in Sudan through more establishments and strengthening of research ethics committees and the review system.

## Mandatory Application of Bioethical Principles and Constitutional Rights in 2019 Abortion Discussion in Ecuador

Claudia Orellana Robalino

Ecuador

Abortion in Ecuador has been widely debated in different fields; the main ethical arguments are the deontological religious (pro-life) view versus the social justice ethics (prochoice). However, these arguments collide with each other they have not adequately addressed the fact that Ecuador defines itself a secular, social justice, and constitutional rights country. That implies the directly and immediately application of human rights and bioethical principles all of them recognize at a Constitutional level. Mainly this paper analyzes the unconstitutional religious slippery slope argument which states allowing abortion in any case of rape, incest, and non-consensual cases will destabilize society; therefore, abortion in those cases is criminalized with prison. The paper demonstrates that 2019 abortion reformations must be talked under the principles of constitutional block and supremacy of Constitution, meaning that bioethical principles, sexual and reproductive rights, right to health, among others, have to be the framework of abortion discussion at the Congress. In conclusion abortion discussion must respect the framework described; otherwise, it will continue to criminalize and force women to become mothers. If the Congress does not approve abortion reformation, another solution is to present a legal consultation at the Constitutional Court to resolve it by binding bioethical principles.

## Is the Paternalist Conduct a Threat for Autonomy of the Patient or is it a Guaranty of the Beneficence of the Medical Conduct?

Raphael Antonio Ovidio, Letícia Maria Akel Mameri Trés, Vanina Avila Melo Vidal Vidal, Marcos de Holanda Pessoa, Drauzio Oppenheimer, Christiane Peres Caldas, Natalia Silva Cavalcante, Sergio Murilo Pereira de Melo

Brazil

Primordially, it must be highlighted that the doctor practice is based on Prima facie principles of the beneficence, nonmaleficence, justice and autonomy. Thus, autonomy is defined as the right of the patient to decide loosely, of ownership of the necessary knowledge to take decision, the treatment that will be executed both in diagnostic investigation and in therapeutic conduct of the disease of the patient. Nonetheless, traditionally, a paternalist tendency is identified in the conduct of the doctor based on the principle of the beneficence and not of the maleficence. However, with the social, cultural and moral changes in the occidental society throughout history, the relationship between doctor and patient has been suffering a process of overhaul because the principle of the autonomy is being more exerted by the patients. This way, an important ethical conflict in the relationship doctor-patient is arousing.

### **Research Ethics: A Health Education Experience Involving Undergraduates and Patients at the Outpatient Clinic of a Brazilian University Hospital**

Marisa Palacios, Simone Silva  
*Federal University of Rio de Janeiro, Brazil*

The paper presents the results of a health education project that involved nine health undergraduates and patients, potential research participants. A booklet, prepared in 2010 by researchers and patient representatives from the university hospital, was used, showing what clinical research and research ethics are and what they can expect from a research project, researcher and the institution.

The undergraduates participated in training in which the topics covered were: clinical research, principlism, ethical regulation of research in Brazil and how to approach patients. They then approached 157 patients, 149 agreed to talk to the team. Of these, 34 declared to be research participants, 148 patients considered the contact important, and 133 reported having acquired new knowledge.

Students could see: some patients who have participated or are participating in research are unaware of their rights, the informed consent, the risks, and benefits; former participants reported not knowing the data and results of the research they helped to develop; that some have the impression of being seen as guinea pigs. As a conclusion, the authors affirm that the dialogical interaction proposed in the project between students and patients contributes to the better formation of future researchers, more concerned with the participant and their rights and also for the dissemination among patients of information about clinical research and bioethics.

### **Significance and Regulation of Ethical Review for Animal Experiment in Hospital**

Qun Pan, Li-Xia Wang  
*Wuchang Hospital, China*

In his paper, the authors expounded the importance of laboratory animal to the medical practice, medical teaching and research in hospital. The new drugs and new technologies which play a great role in hospital cannot be completed without laboratory animals. Experimental animal platform is the indispensable important component of hospital teaching. Laboratory animals is an important support for medical research progress and development is helpful to improve the hospital scientific research level and competitive strength and realize the sustainable development of hospital. In this paper, the significance of protecting and caring laboratory animal to the harmonious hospital construction, heightening the medical ethics of doctors and improve the technological exchange. Besides, the experience of a hospital how to standard the ethical review for animal experiment was also introduced.

### **Iatrogenic Splenic Rupture During a Colonoscopy without Perforation: Case Report and Medico-Legal Implications**

Margherita Pallocci, Saverio Potenza, Filippo Milano,  
Silvestro Mauriello, Giulia Petroni, Michele Treglia  
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Iatrogenic splenic rupture during a colonoscopy is a rare, but known, complication. To the best of our knowledge only few cases have been described in the English literature with an estimated incidence rate to be as low as 0.00005-0.017%. The rarity of this complication raises numerous problems regarding medical professional liability. This because it is not always easy to establish whether the onset of the damage is to be related to a real technical error or whether it should be considered a mere complication. We present a case of a 52-year-old woman who suffered an acute rupture of the spleen after undergoing colonoscopy, in the absence of demonstrated intestinal perforation, which required an urgent splenectomy. In the presented case another matter of a medico-legal nature is related to the failure to foresee such a complication, given its rarity, in the informed consent form signed by the patient.

### **Medical Liability in a Complex Case of Cardiocerebral Ischemic Attack: A Case Report**

Pierluigi Passalacqua, Margherita Pallocci, Michele Treglia,  
Jacopo Giammatteo, Fabio Guidato, Marco Mezzelani,  
Andrea Cammarano  
*University of Rome "Tor vergata", Italy*

Cardiocerebral Ischemic Attack (CCI) is a rare clinical event characterized by a complex symptomatology, including cardiac ischemic symptoms, associated with stroke symptoms; those imply both difficult management of the event and narrow therapeutic windows. The rarity and complexity of this condition still represent a strong topic of discussion because of the lack of both international guidelines and so called "good practices" which could direct physicians in the management of this compound pathological scenario. The lack of specific indications and the presence of so many specific guidelines for each of the two conditions that occur in the CCI, expose physicians to a strong risk of error, with resulting implications for medical liability. In this case report we present the case of a 77 years old man, affected by CCI, who attended a non-PCI center; then we will discuss the clinical implications and the resulting medicolegal aspects.

## Presumed Post-Mortem Donors: The Degree of Information of University Students

Rita Pinho, Cristina Santos, Ivone Duarte  
University of Porto, Portugal

**Background:** Organ transplantation represents the most effective and acceptable therapy for end-stage organ failure. However, its frequent practice often leads to a shortage of organs worldwide. To solve this paradigm, some countries, such as Portugal, have switched from an opt-in to an opt-out system, which has raised concerns about respect for an individual's autonomy. We aimed to evaluate whether young university students are aware of this opt-out system so that they can make informed, autonomous, and conscious decisions, and to identify the factors that determine a positive attitude toward post-mortem organ donation.

**Methods:** An observational cross-sectional study was developed, and a questionnaire was applied to students from six faculties of Oporto University, enrolled in their first year of studies.

**Results:** Of the 841 participants, 60% were unaware of the Portuguese opt-out system. Of the informed individuals, the main sources of information used included social media, internet, and family. Furthermore, only 48% of all participants agreed with the current opt-out system. Female sex ( $p=0.049$ ;  $OR=1.393$ ), knowledge about the law ( $p<0.001$ ;  $OR=4.749$ ), and family as the primary source of information ( $p<0.001$ ;  $OR=2.855$ ) were independent factors associated with a positive attitude toward post-mortem organ donation law.

**Conclusions:** There is a significant lack of knowledge among Portuguese young university students regarding presumed post-mortem organ donation law and its process. Female sex, having family as a primary source of information, and being aware of the presumed post-mortem organ donation law are the strongest independent factors in determining a positive attitude toward the opt-out system.

## Post-Mortem Pregnancy Cases in Poland

Marta Puścion  
University of Warsaw, Poland

The aim of the poster is to present and analyze two cases of post-mortem pregnancies that took place in Poland and that has never been discussed in scientific literature. Presented cases alongside with the legal argumentation based on Polish law will enable to introduce the difficult considerations regarding post-mortem pregnancy from Polish perspective. I shall argue that the decision about post-mortem pregnancy should depend on circumstances of the particular case. Even though the post-mortem pregnancies occur very rarely, it is necessary to establish course of action that has plausible legal and moral justification. My poster will be divided into four parts that relate to different legal and moral issues. First part will focus briefly on the presentation of the facts of the post-mortem pregnancy cases in Poland. Second part will discuss which entity shall be a decision-maker in the post-mortem pregnancy. Thirdly, I will consider foetal perspective and his legal status. I propose that the interests of the foetus should be considered but never play primary role.

Finally, I will focus on the pregnant woman's perspective: her legal status, interests and rights. I conclude that the woman's right to self-determination extends beyond grave and her wishes should be decisive.

## Global Benevolence or Self-Advancement Abroad? Rethinking the Ethics of Undergraduate Student Participation in Short-Term Experiences in Global Health

Nishita Pondugula  
University of Texas, USA

Methods of improving Short-Term Experiences in Global Health (STEGHs) have been widely discussed over the past couple decades with prominent scholars like Matthew DeCamp and Irmgard Bauer arguing that STEGHs must accept greater accountability in their work. However, these perspectives discuss STEGHs that utilize physicians and medical trainee volunteers; differences for undergraduate volunteers have not been adequately addressed. This project examines the unique ethical issues that arise from undergraduates' lack of medical expertise. Such issues include the effects of limited resources and justice concerns on both local populations and undergraduates, potential for medical harm, issues arising from cultural differences, neo-colonialism, and exploitation. Rectifying these insufficiencies requires multifaceted adjustments: clinical care provided by STEGH participants must be informed and shaped by relevant research findings and STEGH organization leaders must be more considerate with volunteer selection and preparation. To begin involving research methods in STEGHs, measurement of long-term health outcomes through sustained interaction with the local community is required. In order to improve volunteer practice internally, STEGHs must consider the intention of the student in volunteer selection and must discuss relevant ethical concerns with volunteers. Current STEGH practices are insufficient and must change significantly to ensure they are improving global health.

## Disappearing Drugs: Lost, Stolen, and Discarded Medications in the Homeless Community

Amy Reese  
Yale University, USA

People who are homeless face health disparities due to their living conditions. Using the moral theories of deontology, virtue ethics, and utilitarianism, it can be determined that people in these communities deserve medical care. One burdensome disparity is the risk of having their maintenance medication lost, stolen, or discarded by other people. This problem is not addressed in the literature. The importance of this problem is explained in this paper by demonstrating the consequences of not being able to take anticoagulants, antiretroviral therapies, and antipsychotics. These medications are vital to the life and well-being of these people because without them, worse acute illnesses or even fatality can occur. Without anticoagulants, blood clots can occur; without antiretroviral therapies, opportunistic infections are a possibility; without antipsychotics, psychosis may occur. Pharmacists and homeless outreach organizations can help alleviate this disparity: pharmacists can dispense smaller amounts of medications than the normal 30-day supply and outreach organizations can store medications for these people. In this paper, it is argued we have a moral responsibility to give care to people in the homeless community and help decrease this health disparity.

## **The Final Countdown: You Can Not Choose the Final Disease, but You Can Select the Outcome – Euthanasia Vs Palliative Care**

Victoria Rial-Plaza  
Yale University, USA

End-of-life situations lead to complex decisions that result in ethical discrepancies. However, there has not been a global consensus of what is the correct behavior in these circumstances although it is a subject of interest that concerns us all as mortal human beings. This paper will investigate the reason for these disagreements with a technical and bioethical approach. With the aid of Beauchamp and Childress' Principles of Biomedical Ethics and the support of reference books and articles and real experiences, the aim is to reflect on controversial issues at the end-of-life care culminating in why palliative care could be the best outcome to a terminal illness, leaving behind immediate-death decisions known as euthanasia or physician-assisted suicide. Therefore, this work defends that making good use of palliative care should fulfill most patient's expectancies at the end of life; being an act that both improves life's quality and respects death without hastening or delaying it deliberately. In conclusion, this project focuses in the different points of view in an ethical dilemma that entails serious family, social, medical, ethical and political consequences between choosing an immediate death or perhaps, a gradually relief of pain as the answer to an end-of-life situation.

## **Ethical Aspects of the Decision to Deactivate the Implantable Cardioverter Defibrillator (ICD)**

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<sup>3</sup>Universidad Del Rosario, Colombia

The increase in life expectancy, the availability of technology has led to the increase of patients with cardioverter-defibrillators (ICD) they can present activations due to the deterioration of their clinical condition, which produce painful symptoms, adversely affecting end of life and dignity. It is important to consider the option of reorientation of vital treatment, which is the possibility of deactivating the device to prevent electric shocks at the end of life where death is inevitable, compromising the quality of life of the patient and affecting a dying with dignity. The study was conducted through interviews with ten physicians (Cardiologists, Electrophysiologist) to know their concepts about the deactivation of the ICD. The physicians interviewed, only one claims to discuss the deactivation of the device preimplantation, most specialists say they do not discuss this issue in the preimplantation phase, they prefer to explain how the device works, the purpose of the therapy and the possible complications, they consider that it is not an easy topic to deal with patients in the initial stages of the disease, there are fear of talking about these issues and there is still a taboo around death, most come to this discussion with their patients or relatives at an advanced stage of their disease, or by the appearance of comorbidities such as cancer. We believe that ethical aspects should be discussed in ICD patients and their relatives.

## **Recognize Difference to Promote Women's Education**

Marie-Alice Riault, Sophie Trarieux-Signol, Valérie Blaize-Gagneraud, Maryse Fiorenza-Gasq  
Espace de Réflexion Ethique Nouvelle Aquitaine Limoges, France

Poverty, socio-cultural inequalities, forced marriages, early pregnancies or gender-based violence in schools still prevent a large number of girls from accessing to so-called "academic" education. However, it contributes greatly to reducing gender inequalities. Yet cultural diversity or socio-economic levels do not appear to be the only factors responsible for the exclusion of women from school. Indeed, and this is less well known, menstrual precariousness is at the root of the marginalization of more than 500 million women worldwide, particularly in the school environment. The lack of sanitary facilities necessary for the respect of their privacy and their health or the restricted access to the hygienic protections have a significant impact on the schooling of the girls. This inequality is observed in developing countries but also, more surprisingly, around us, and illustrates from an unusual and unknown angle the extent of the challenge of access to education for girls from the world.

Is it ethically conceivable that a biological function prevents women from having access to proper education?

To hope for equal access to education, we must recognize the differences, respect them and make everyone aware of this problem, to propose practical actions.

## **Role of Multidisciplinarity in Palliative Care: Case Report**

Marcia Rodrigues Bio Araujo<sup>1</sup>, Lucas Magalhães<sup>1</sup>, Cristina Bueno Terzi Coelho<sup>1</sup>, Daniele Sacardo<sup>1</sup>  
State University of Campinas, Brazil

A.R., 33 years old, 23 weeks pregnant, sought maternity with a cholangio resonance with expansive lesion suggestive of cholangiocarcinoma. The gastro surgery team ruled out the possibility of surgical approach for the extension of the lesion. The oncology contraindicated chemotherapy treatment. From then on, the palliative care team was called. The possibility of trying to prolong the life of the patient with her consent was considered, trying to bring the pregnancy to a viable point for the fetus. However, malformations and serology confirmed acute cytomegalovirus infection and estimated weight of 425 grams. We consulted neonatology, which confirmed the severity of the malformations observed and their impact on a preterm newborn. A family conference was held with midwifery, palliative care, gastro surgery and neonatology. Only from this meeting on was it possible to define the care plan, focused on comfort and welcoming of the family. We involved the nursing staff of the inpatient unit, paying attention to the emotional distress of the team inherent in a case with such a disastrous outcome. The palliative care team in this case was crucial in uniting the teams involved in the same goal of comforting the family, and avoiding unnecessary suffering related to therapeutic obstinacy.



## Descriptions of the Legal Framework of Medical Research in Norway

Fredrik Rongved, Anna Stephansen  
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Research in Norway is regulated by the Research Ethics Act, the first version of 2006, later revised in 2017. Only a researcher within the field of medical and health research, however, is required to apply for pre-approval of a research project from an Ethics Committee (EC). The Health Research Act has been regulating this field of research since the 1st of July 2009.

The General Data Protection Regulation (GDPR) went into force in Norway the 20th of July 2018, as within the other member states of the European Economic Area (EEA). The GDPR impacted the regulation of multiple sectors, the health sector among others.

This poster will describe how did the integration of the GDPR impacted the legal framework regulating medical and health research in Norway. The poster will focus on the legal significance of a decision from the regional ECs and the increased accountability of the research institution. Finally, a short comparison will illustrate the similarities of the chapter of the Health Research Act regulating the use of health data and the GDPR.

## The Role of the Gerontologist in Palliative Care

Ana Roque, Francisca Rego  
University of Porto, Portugal

Gerontology studies the human aging to ensure that it is well-assisted, particularly in the terminal phase of life. Aging, accompanied by illness, dependence and suffering is associated with an intensification of the need for palliative care.

The aim is to systematize the published scientific production on Social Gerontology and Palliative Care, analyzing its contribution and explore the knowledge of health professionals about the role of gerontologists in Palliative Care.

The results refer to the importance of multi/interdisciplinarity and the recommendations for performance improvement in Gerontology in Palliative Care. The knowledge of professionals about the role of gerontologists is unclear. The increase in the aging rate in Portugal requires greater commitment from educational institutions in the training of professionals to maximize the well-being of the elderly. The importance of non-pharmacological interventions plays a relevant role in the skills of the social gerontologist in Palliative Care, whose approaches has been successfully tested.

More research is needed on Social Gerontology in Palliative Care, as well as the development of specialized skills in this area, aimed at different professionals, namely in the field of Gerontology. The research and evaluation are essential for changes to meet the real needs of older people in today's society.

## Medical-legal Aspects of the Prenatal Diagnosis: An Unresolved Topic

Umberto Rosini, Martino Maesani, Matteo Antonio Sacco,  
Carmen Scalise, Angelica Zibetti, Fabrizio Cordasco,  
Francesco Maria Galassi, Elena Varotto, Santo Gratteri,  
Pietrantonio Ricci, Isabella Aquila  
"Magna Graecia" University of Catanzaro, Italy

With this work we want to address the delicate question regarding the complex issue of the Wrongful Life Claim (WLC), therefore if a person born with a malformation that marks his life, and for which he is certainly not responsible, has the right or not to ask for a compensation. The serious permanent handicap is mainly related to the lack of information from the doctors to the mother, who for this reason was unable to determine herself to the voluntary termination of pregnancy. According to consolidated Italian jurisprudence, the right to compensation concerns only the next of kin while other jurisdictions admit the right to compensation for that specific person born with disabilities for non-voluntary termination of pregnancy and for this reason forced to live a life neither desired nor desirable in a hostile context, in the economic disadvantage and in the family, relational, social and work-lucrative hardship. However, the ethical difficulties that exist on the themes of the WLC derive from the well-known concept of the sacredness of life and from the distinction between the malformation that marks life and that which falls within the mere defects that don't make existence seemingly useless as it is unbearable to live.

## Justifying Abortion Laws: A Study of the National Factors Influencing Abortion Legislation

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<sup>2</sup>University of Tokyo, Japan

With the global debate on abortion shifting from the focus on individual privacy in Roe vs Wade to that of female autonomy, a strong correlation between a country's abortion laws and level of gender equality would be expected. Although a positive correlation was observed between global gender equality rankings (derived from the World Economic Forum's 'The Global Gender Gap Report 2018') and a self-constructed abortion liberalization ranking (derived from the legal grounds for abortion in each country, as categorized by the Center for Reproductive Rights 2019), a significant number of outliers were apparent. By conducting closer case studies into individual countries, especially the Philippines, Laos, Yemen, the United Kingdom and China, it is evident that abortion laws arise from a much more complex combination of political, cultural and social conditions. These are inclusive of, but not limited to religious influence, medical accessibility, historical events and government authority. Thus, while many studies have investigated the private factors that influence an individual woman's decision on abortion, it is also necessary to discuss the national factors influencing the public perception of abortion when considering its legalization.



## Respect for the Bioethical Principles of Autonomy and Justice in Medical Care in Mexico for Underaged Patients, by Implementing the Informed Consent Form

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The relevance of honoring the Bioethical Principles of Autonomy and Justice related to medical care for minors, including pregnant adolescents, in Mexico. Minors have the right to express their will in an informed consent over a diagnosis and the corresponding medical or surgical procedures. This is an ethical demand, considering that there are at least 39.2 million minors living in Mexico, representing 32.8% of its total population. This is a legal issue, as Mexican legislation grants legal capacity to bind only to those over 18 years of age. Nevertheless, the principle of superior interest of minors provides a solution in international law. This was embraced by the UN on November 20, 1989 to protect the rights of minors worldwide. Our Constitution provides so in its article 4, legal precept interpreted by the Supreme Court as follows: "It grants efficiency to legal acts entered by minors, provided those are in their benefit". Thus, the implementation of informed consent form by minors for medical care in Mexico is viable. It is necessary, then, to develop the necessary public policies to detail benefits, justification, and control, by certifying the adolescents' mental capacity and maturity regarding medical diagnosis.

## What is the Role of the Local Bioethics Commission in the Proper and Successful Implementation of Scientific Research in Surgery?

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**Objectives:** to present the results of work of the local bioethics commission in the National scientific center of surgery.

**Materials and methods:** As a material for the analyses there were used the dates from the A.N. Syzganov NSCS.

**Findings:** The local commission on bioethics in scientific centre of surgery was set up in 2006. Composition and position of LBC approved by the order of the executive. The present LBC consists of 11 people, 2 unaffiliated member which is obligatory to include.

The work of local commission on bioethics was carried out in several main areas: ethical examination of scientific and technical programs, participation in multicenter clinical trials (international), new methods of treatment, assessment of compliance with ethical standards of clinical trials of the effectiveness and safety of drugs, as well as published guidelines and monographs. During this period, more than 17 scientific and technical programs, over 15 new treatment methods, 8 clinical trials of new drugs, 11 guidelines and 3 monographs were ethically evaluated.

**Conclusion:** The work of the local bioethics commission plays an important role in monitoring scientific research in surgery, requires dynamic ethical estimation of obtained results, promotes to successful and proper implementation.

## The Impact of Female Genital Mutilation on Victims' Mental Health: A Review of Literature

Matteo Antonio Sacco, Fabrizio Cordasco, Carmen Scalise, Angelica Zibetti, Martino Maesani, Umberto Rosini, Orazio Malfa, Luigi De Aloe, Maria Manno, Santo Gratteri, Pietrantonio Ricci, Isabella Aquila

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Female genital mutilation (FGM) represents a serious violation of human rights but, unfortunately, it is still a very common practice involving about 200 million of women around the world, with risk of stigmatization for who oppose it (1). FMG shows not only physical effects (infections, infertility, menstrual disorders) but also significant mental and emotional consequences. The purpose of this review is to investigate the psychological impact of FMG on the mental health of victims. A review of literature was performed through the PubMed NCBI search engine, and papers emerged by entering the keywords female genital mutilation and mental health were evaluated. Data analysis showed a greater vulnerability to psychiatric disorders such as depression, anxiety with somatic symptoms, post-traumatic stress disorder, affective and personality disorders but also sexual dysfunctions with devastating psychological consequences occurring in childhood or adolescence (1-3). Severity of mental disorders seems to be accentuated by the risk of polyvictimization, i.e., by the occurrence of these practices in a social context of emotional, physical or sexual abuse. The review emphasizes the urgent need to identify strategies aimed at preventing the phenomenon, facilitating access to treatment including close psychological support for victims.

## Work and Right to Health: Excluding Options in Present Brazil

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If everything can be bought, individual health can also be confiscated for the benefit of another. This is what happens in some forms of labor that exploit human labor to the point of survival rather than full life. Happens in Brazil, where the struggle to guarantee the right to health has lost significant battles: maintenance of the laws and norms within the legal system that constitutes the basic legislation, which protects the worker's health, bound to Health and Work issues.

Boosted by alterations that happen in the globalized work sphere, supported by actions of the government, that submit the Health Care to the economic policy of withdrawing resources from social politics, in Brazil have happened infra constitutionals changes that compromises the health. The unemployment and the new ways of surviving are issues that the economically underprivileged class is forced to deal with, and it increases the risk of getting sick and dying because of the work.

Multidisciplinary actions, which encourage the companionship and solidarity among workers, techniques that allows the empowerment of concepts like 'socially developed illness', 'worldwide division of work', can decrease the burden of individual suffering, help in the quest for collective answers that face the alterations in the world of work. This paper is a case report in the municipality of Campinas, Brazil.

## Ethical Issues of the Treatment of Chronic Pain in Older Persons: Use of Opioids

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Pain is a common symptom in older people. It is possible that pain is underreported in older persons due to an incorrect belief that it is an inevitable part of aging. Chronic pain is pain that lasts more than six months. It is negatively affecting many aspects of the person's life, socializing, performing daily activities if it is not treated. It is often accompanied with psychological illnesses, such as anxiety, depression, and loss of self-esteem. Painful conditions are often caused by arthritis, back pain or muscle pain, cancer, headaches, strong viral infections, or addiction illnesses.

Opioid analgesics are potent medications, with confirmed efficacy for the treatment of moderate to severe pain. These drugs are commonly used in older persons. However, there is insufficient evidence regarding safety of opioids in older patients. One of the reasons for this is the lack of randomized, controlled clinical trials. There are also some discrepancies between guidelines, which recommend the use of lower doses of opioids in older patients, and the findings in the literature which suggest that pain is often undertreated in this age group. There are numerous ethical issues related to the use of opioids in patients with chronic pain.

## Therapeutic Abandonment as a Movens for the Euthanasia Pressure

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The progress of medicine and technology has determined on the one hand an increase in life expectancy, but on the other hand more chronic-degenerative diseases, a prolongation of the phase of decadence that precedes death as well as an increase in terminal illnesses, with inevitable physical and existential suffering and an enormous waste of economic resources.

According to the 2009 Final Palliative Care Report, in Italy, over 250 thousand people reach the end of their lives every year through a phase of terminal disease. This figure has been increasing over the last decade. In 2017 there were 230 hospices (with public management only in just over half), with about 2500 beds. Only in a low percentage of these there is a complete structure of palliative care, and for the most part no home care is provided (continuity of hospital-home care). Diffuse dysthanasia accompanied likewise to a rampant therapeutic abandonment of patients in the terminal stages (due also to the absence of health measures and economic investments aimed at guaranteeing an adequate care-therapeutic network), would partly justify the euthanasia thrust that is gaining ground in Italy. Based on our experience, the resilience to physical suffering is impaired by insufficient health care.

## Terminal Sedation and Bioethics: Scenery in Italy

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Terminal sedation is intentional reduction of the conscious with pharmacological treatments, until its loss, for the purpose of abolishing, the perception of a refractory symptom [1]. Refractory symptoms more frequent are dyspnea (35-50%), delirium (30-45%), nausea and vomiting (25%), pain (5%) [2-4]. Ethical justifications of the terminal sedation find foundation both in the "principle theory" both in more specific ethical theories such as the ethics of quality of life and of the sacredness of life [5]. Terminal sedation is morally acceptable, therefore, if there is patient consent, if it improves your quality of life without cause his death. Indeed terminal sedation should not be considered synonym of euthanasia because it doesn't shorten life of ill. Even, sedated patients often live longer than conscious ones [6]. It's born in Italy the Law n. 38/2010. Despite its univocal definition, terminal sedation still causes confusion currently, in our country, for this reason it isn't widespread and know. Terminal sedation must be considered share of the care relationship. Only by adequately informing the patient and properly training healthcare professionals, we can create hospitals "without pain".

## Bioethics Challenges in Military Medicine: The Israeli Military Nursing's Experience

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**Background:** The Israeli Medical Corps was established in 1949. In the same year, most military hospitals were closed gradually or transferred under the Ministry of Health authority. Since then and during the first 35 years in which the State of Israel was formed, Military nurses served parallel in civilian and military arenas faced both with immigration's health and military ethical challenges.

**Methodology:** The study includes historical research methods including 116 interviews with Israeli military nurses and their peers at the Ministry of Health.

**Findings:** The Israeli military nurses' area of action was varied. The recruiting and training processes were unique and were adapted to the country's national missions. Recruited nurses participated in all of the Israeli five wars between 1948-1983 and also took a major position in immigration absorption and civilian peripheral hospitals, treatment of prisoners of war, and refugees in humanitarian crisis delegation.

**Conclusion:** The Israeli military nurse's served both in civilian and military missions and were faced with ethical aspects such as limited medical resources and moral dilemmas. Findings show nurses were acted creatively and leaded other service persons according to ethical and moral guidelines in times of stress and lack of resources.

### Addiction Research Ethics and Principles: What Does it Mean to Drug Users in a Malaysian Setting

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According to the world drug report (2019), 35 million people worldwide suffer from drug use disorders while only 1 in 7 receive treatment. Many countries, including Malaysia have no guidelines on how to carry out research among drug users. Although there have been substantial discussions about the conduct of ethical drug use research, very little has been done to gauge the drug users' voice. We therefore set out to elicit drug users' views and perceptions about addiction research ethics and principles while participating in research. Our aim is to assess drug users' conception of fundamental ethical principles such as risks & benefits, respect for persons and informed consent. What is their viewpoint on financial compensation and non-coercive research participation in drug use research?

Focus group discussions involving drug users, solicits participants' attitudes, perceptions, knowledge and experiences. Hypothetical scenarios and open-ended questions facilitate more detailed and in-depth discussions pertaining to ethical concerns in research participation.

By moderating focus group discussions with this key population, we can shed much needed light on their understanding of addiction research ethics and its principles. The information gained may eventually pave the way for the development of an enlightening drug use research guideline.

### Environmental Bioethics: Responsibility for a Sustainable World

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The present work summarizes environmental problems and their possibilities of interpretation and solution. Highlights the role of Bioethics as a discipline that can interpret the place of man in nature, as well as justifying the need to address the environmental problem, not only from ecology, but under from the analysis of socio-cultural factors, the economic dependence and, in this respect, the gap between rich and poor countries. The work considers theoretical and philosophical elements that interpret the rupture of man with nature and its resulting irresponsibility, offering a critical explanation of environmental bioethics in the face of environmental issues. The human being has the moral obligations to act thinking of others, to avoid the destruction of human existence and to watch over the care of nature for future generations, in order to achieve quality of life, in this sense, the transfer harmful technology from developed countries should be avoid, based on ethical principles of non-maleficence. Humanity's bioethical efforts must aim to do science with conscience, for a reconciliation of human beings with their habitat, harmonizing the dignity of man with the dignity of nature, based on Sustainable Development.

### A Right to Peacefully Die: Physician Aid in Dying in Dementia Patients

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The issue of physician aid in dying has been widely debated in the field of bioethics. However, the arguments in this field have not addressed the issue of physician aid in dying in patients with dementia. This paper addresses the issue of physician aid in dying with a focus on eliminating the "terminally ill" requirement for pursuing this practice. This paper will advance the argument that patients have an inherent and fundamental right to a dignified death and should be able to choose physician aid in dying before they lose capacity to do so. This paper argues that the option of physician aid in dying should be available to patients with dementia at the start of their diagnosis and should eliminate the precautionary eligibility of being deemed "terminally ill" with a 6-month prognosis to live in order to have the procedure.

### Deprivation of Legal Capacity: Legal Norms and Practice in Serbia in the Light of the Human Rights Standards

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By emphasizing that disability is a part of diversity of the mankind (rather than a consequence of the individual's impairment) the Convention on the Rights of Persons with Disabilities (2006) made a revolutionary shift in disability policy. The right to the legal capacity is established as a basic human right and universal value shared by the entire mankind. There is no legitimate reason for depriving a person of her legal capacity; substituted decision is no longer acceptable since it deprives a person of the right to make autonomous decisions about her life and reduces her into an object rather than a subject of law. In the Serbian legal system legal capacity is the basic characteristic of every individual, but only entails person's capacity to hold rights and duties. Although Serbia has ratified the CPRD in the year 2009, a law which allows the court to deprive or limit legal capacity of an adult is still in force. Person deprived of legal capacity is put under guardianship with the authorization of her guardian to make legally effective decision on her behalf. Number of persons deprived of legal capacity is increasing in Serbia: 12.732 persons in 2015, 13.030 persons in 2016. and 13.075 person in 2017. year. In our contribution we present actual legal regime and the judicial procedure for deprivation of legal capacity in Serbia in the light of human rights standards and new paradigm of the equality promoted by CPRD.

## Medical Ethics Questions in Serbia: Pain Management in Children

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The management of pain is always actual issue, especially in pediatric population as a large and very vulnerable group. Today, many myths about pain in children are rejected: very young children don't have capacity to feel and remember pain. Untreated pain early in life can develop emotional and psychological changes and lead to chronic pain in adulthood. Pain assess in children can be difficult, but it is developed many age-specific pains management tools. It can be assessed through vital signs, behavioral observation, and children reports. It is important that communication will be adapted to the child's age and developmental level. As adults, children can suffer from different painful conditions: headaches, arthritis, cancer, etc. Although some painful conditions can be different in childhood. For the successful pharmacotherapy of pain in children it is necessary knowledge of drug mechanisms as well as difference in body composition and physiology functions in infants and children compared with adults. This causes differences in the choice of drug, formulation, dose and dosage regimen of the drug in childhood. Based on research data in pediatric pain management it is necessary to develop guidelines for the management of pain in children and use recommendations into routine clinical practice.

## Can the Right to Therapeutic Self-Determination Justify the Assisted Suicide?

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The law 219/2017 gives anyone the right to therapeutic self-determination. However, it doesn't tell anything about assisted suicide. A recent judicial case turned on the spotlight again on the end-of-life theme. The Constitutional Court ruled on the constitutional legitimacy of the article 580 CP. It punishes whoever persuades someone else to commit suicide, reinforces his suicidal purpose or facilitates its execution in any way. In the spirit of a loyal Institutional cooperation, the Court submitted the Parliament any decision about this theme. The long-lasting silence of the Legislator led the Court to declare anyone who facilitates the execution of the suicidal purpose of a patient undergoing life-sustaining treatments not punishable according to the article 580 CP, under specific conditions. The patient must be affected by an irreversible pathology, that causes him an intolerable psycho-physical suffering, but he must be able to self-determine. Non-punishment of suicide aid requires specific precautions in order to prevent any risk of abuse against particularly vulnerable people. However, there are still many gaps to be filled: legislative action is essential. It will be necessary to overcome the difficulties concerning how to carefully test the patient's will and how to check the punctual presence of required conditions.

## Sudden Death Occurrence during Assault with Neck Compression: A Neurally-Mediated Mechanism Induced by a Direct Vagus Nerve Compression

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Claudia Scipione, Celeste Conte<sup>1</sup>, Filippo Milano, Silvestro Mauriello,  
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Fatal neck pressure due to manual strangulation is a relatively common event. Sudden deaths that happen in the first seconds of pressure are attributed to nerves' effects. As reported in literature, the mechanism is carried through a reflex arc in which the afferent (sensory) nerve impulse arises in the carotid complex of the nerve endings, but not directly in the vagus trunk. On the contrary, we describe one such fatality. The body of a 25-year-old man came to our attention in our institute of legal medicine. According to testimonies and investigations the victim had a domestic fight with his brother. After a verbal assault the victim had been grabbed by the neck and immediately fell down and died. No CPR was performed and when rescuers arrived, he was declared dead. At the external examination there were only two little oval-shaped superficial abrasions in the left cervical region. No other signs of violence were detected. Neck's dissection only revealed blood infiltration in the tissues around the vagus trunk in its cervical tract. All other structures of neck, thorax and abdomen were uninjured. The cause of death was attributed to neurally mediated cardiac arrest induced by direct vagus nerve compression.

## Medical Liability in Italy: One Year Analysis of Civil Court of Rome

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Enrico De Dominicis, Pierluigi Passalacqua, Giulia Petroni,  
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The doctor-patient relationship has always been characterized since ancient times for the intensity of emotions that the patient feels towards the doctor. Emotions that can be either of enormous gratitude towards the one who is seen as a bearer of health or of strong resentment in case of error or disappointment for not achieving the desired result. This emotionality has increased today, especially in cases where the desire for health remains disappointed. The intensification of this feeling is attributable to the change in the figure of the doctor who, from a hieratic bearer of health, has become a health service provider. In Italy, the change of the doctor and health professional feature, partly acknowledged by the Legislator too, has led to a significant increase in civil disputes over professional liability and public spending for compensation. In order to investigate this phenomenon, we carried out a study in collaboration with the Court of Rome analyzing the sentences issued between January 2018 and February 2019. 290 judgments were then analyzed by extrapolating the specializations most involved, the percentage of conviction, the people involved, the type of damage suffered by the patient, and the amount of compensation paid.



## "All of Us?" Distributive Justice Considerations in Precision Medicine Research Programs

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The All of Us Research Program (AoURP), slated to be the largest longitudinal research study in US history, is a federal effort to compile one million individuals' genetic, phenotypic, and behavioral health data for purposes of developing precision medicine (PM) therapies. As one of the first programs to compile holistic medical information for large-scale study, AoURP will play a pivotal role in the incorporation of PM techniques into daily clinical practice. However, public health experts have raised manifold concerns about the ramifications of this individualized clinical strategy on population health priorities. This project identifies a common normative locus in these concerns: the just distribution of PM research benefits across diverse racial and socioeconomic groups. Despite this shared ethical priority, a means of evaluating the allocative fairness of research agendas and protocols has yet to be developed. This project posits Norman Daniels' framework articulated in *Just Health*, which stipulates four conditions for a "fair process for setting priorities among health needs," as an ideal methodology for this task. Using AoURP as a case study, this project develops ethical procedural recommendations from each condition, which may be adopted by national PM research programs across the globe.

## The End-Of-Life Choices in European States: Analysis and Comparison

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In European States end-of-life choices are differently regulated. In some States euthanasia is allowed (the Netherlands, Belgium, Luxembourg, Spain). In other ones only assisted suicide is permitted (Switzerland, Germany). Moreover, the German Federal Constitutional Court recognized the general right to suicide for all citizens. In other European States (France, the United Kingdom, Italy...) suicide aid isn't allowed yet, although the case-law is showing signs of openness to this practice. In Italy, the Constitutional Court has recently declared that who facilitates the execution of a patient's suicide, under specific conditions, isn't punishable. The Court of Strasbourg gave everyone the right to decide how and when to die, denying, however, the existence of a right to suicide; therefore, if it's necessary to guarantee every person the right to die with dignity, it's necessary to question the limits of the availability of life and, despite the wide discretion that characterizes the provisions of European States about the end-of-life theme, not to indulge in choices suggested by particular political, economic or social views. In conclusion, it's necessary to guarantee the widest protection of the dignity, freedom and autonomy of the individual about a choice as extreme as that on the end-of-life one.

## Medical & Non-Medical Human Sex Selection in IVF: Ethical issues & Controversial Developments

Marta Vaillant  
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Given the controversy between medical versus non-medical justifications for sex selection in IVF, the moral permissibility of this practice is extensively debated.

Recently, the fields of medical and political ethics have begun to legislate laws affecting sex selection, focusing on its ethical and social consequences: medical tourism and family balancing. The purpose of this paper is to introduce greater clarity to discussions of sex selection for both medical and non-medical reasons and their ethical issues. Specifically, this paper examines to what extent is sex selection morally justifiable and why the life of a male embryo is valued more than the life of a female embryo. This Project also establishes that there is a significant moral difference between using IVF for natural childbearing purposes and using the same technology with the intention of sex selection.

In conclusion, this paper sheds new light on the ethical analysis of sex selection, which is now considered a whim more than as a necessity.

## Information, Communication and Fake News. Bioethics of Training in Public Health Service in the Digital Era

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The admittance to information and communication channels concerning Health might involve, in case of entry into sites, without a good reference, risks of false alarms or fake news. That's why we must consider the limits of the digital era especially with regards to the knowledge needs of a fragile person, who might be vulnerable and could not understand the importance of the (his-her) role concerning (her- his) health.

At this point, human communication and personal discussion are extremely important because the answers are not always available through research. The person needs to have the right information about his health, to get involved consciously and to share the choices which concern himself. For this reason, it is important to look for a trustable relationship between the patient and the doctor, assuring professional, correct and sure communication.

The role of training is strategic and it must be taken up to understand the needs of the person and the human frailty, particularly when the person is overwhelmed by anguish and by uncertainty concerning health.

Training must be untiring and accomplished through a many-disciplinary, suitable and useful confrontation and also opened to different races, within easy reach to differently-able people.



## Be Right Back: The Incidence of Law on the Postmortem Scenario and the Dark Reflection of the Digital Society

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The objective of the present study is to discuss, for the first time in the academic sphere, the Personality Rights – consecrated subject in Civil Law – considering postmortem, based on the plot presented in the science fiction *Black Mirror*, especially in the episode “Be Right Back” (S02E01). Initially, it was attempted to visualize the normative gap created with the influence of the mediatic revolution, a process that allows – through artificial transcendence – the mechanic creation of the ficta presence of someone already proven dead, without their previous consent in life. Furthermore, through a psychological analysis of grief, the effects of the exploitation of virtual relations in the construction of the post-human will be discussed, in the context of digital art that seeks to imitate something legally extinct as a result of death – in this case, the juridical personality. It is intended to create an intersection among the cybernetic world, Bioethics and the development of emotional bonds organically inexistent, with Phyto of concluding what would be the best system to ensure the guarantee of human rights in the postmortem scenario.

## Research Integrity Education for Japanese University Students

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**Introduction:** In recent years, research misconduct has been a reoccurring problem in Japan. In 2014, the Japanese Ministry of Education, Culture, Sports, Science and Technology, urged all national and private universities to conduct research integrity education. However, there is no standard educational method in Japan, and few studies have been conducted on effectiveness assessment. In this study, we considered ways to systematize effective research integrity training through practice and evaluation.

**Method:** In a class titled “Science and Society” at Jichi Medical University, we conducted case studies using a research misconduct prevention training DVD provided by the Japan Science and Technology Agency. Anonymous questionnaires were administered before and after the training. 30 freshmen medical students participated. Since all participants will be medical doctors, it is crucial that they learn about such ethics from various viewpoints.

**Discussion/Conclusion:** The results revealed students’ interests regarding research integrity, and, among other things, the attitude necessary to prevent research misconduct. As teachers are required to provide appropriate explanations for the behavioral styles of scientists and details on how such behavior styles are evaluated, research integrity training approaches are necessary for teacher development programs.

## Exploring Patients’ Autonomy in Cardiopulmonary Resuscitation (CPR) in Malaysia

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A patient’s autonomy during emergency CPR is restricted due to the urgency of the situation and patient’s inability to express his or her wishes during the arrest. Hence, in such situation, the concept of presumed consent is applied. This concept involves the treating physician imagining themselves as the patient and would act on the balance of benefit and harm. Once this balance is tilted towards harm, physician should decide not to initiate the resuscitation. This however, should not be the reason not to respect patient’s previous wishes if there were any. Advance medical directives (AMD) serve as an assurance that the right of patient to make autonomous decisions is being adhered to in anticipation of a situation when they might lose their capacity. In Malaysia, AMD is limited to cultural conditions and the lack of exposure to AMD. Although the Malaysian Code of Medical Ethics has encompassed AMD to be taken into consideration, there is still no legislation available in Malaysia. The practice of emergency CPR in Malaysia has been guided mainly by the physician’s presumed consent unless patients have AMD. The limitation of patient’s autonomy in emergency CPR is perhaps limited by the inadequacy of AMD legislation in Malaysia.

## Health, Human Occupation and Justice

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Occupational justice is defined as “the justice that recognizes occupational rights to including participation in everyday occupations for all persons in society, regardless of age, ability, gender, social class, or other differences” (1). The study of this theme highlights the fact that people may be deprived, contained and alienated from engaging in occupations that provide meaning and balance to their lives (2). A narrative review was conducted to discuss the relationship between the concept of occupational justice with health and well-being. In the last decades, the connection between health, occupation and well-being has been more deeply discussed, with emphasis on the influences of human occupations on physical, mental and spiritual health (3). Assuming that since all people are occupational beings with different needs and from different natures, meeting these needs is a matter of health, which makes it a matter of justice. Occupational therapists are qualified to recognize areas of occupational injustice and to support policies, actions and laws that enable people to engage in occupations that have purpose and meaning (1), ensuring the principle that “People have the right to participate in a range of occupations that enable them to flourish” (4).

### The Constitutional and Legal Normative Force of the Brazilian Code of Medical Ethics

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It is a fallacy to say that the Brazilian Code of Medical Ethics is less relevant because it was instituted by means of a resolution, hierarchically inferior to the law and the Constitution. The principle of professional freedom, which is stamped on the list of fundamental rights and guarantees of the Constitution of the Federative Republic of Brazil (CRFB, art. 5, XIII), determines the free exercise of any profession, provided the professional qualifications established by law. In turn, article 5º, d, of Law nº 3268/57 delegated to the Federal Council of Medicine the elaboration of the Code of Medical Deontology that contains the rules to be followed by physicians in the exercise of their profession. The current Brazilian Code of Medical Ethics is regulated by CFM Resolution nº 2217/2018. Thus, it is clear that the resolutions of the Federal Council of Medicine have valid and existing normative character, subordinating themselves to the hierarchically superior legal system: the law and the Federal Constitution. Therefore, they are not the so-called "autonomous regulations", which are prohibited in the Brazilian order, since they did not go beyond the limits of regulatory power. Therefore, the Resolution that instituted the Code of Medical Ethics has the constitutional and legal protection.

### Do Young Doctors Know the "Living Will"? Cross-sectional Study among Resident Doctors of the University Magna Graecia of Catanzaro

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**Introduction.** In 2018, in Italy came into force the law 219/2017 on subject of end of life, commonly called "living will". This law states the possibility for each person to express their will regarding the health treatments they are willing to undergo<sup>2</sup>. It highlights the role of physician as responsible not only to mere survival preserving, but also for alleviating the suffering and safeguarding each patient from the abandonment risk. According to a national research<sup>3</sup> the 72% of the population know this law, but only 19% declare a detailed knowledge against 28% who never heard about it. The aim of this study is to assess the knowledge of the law 219/2017 among resident doctors of the University of Catanzaro. **Methods.** A cross-sectional study will be conducted and an anonymous questionnaire will be administered using Redcap software. Descriptive analysis will be performed and it will be estimated the prevalence of doctors who know the law with their 95% interval confidence. **Results.** The data collection is ongoing. Currently, in the study, 362 doctors have been included. **Conclusions.** It is essential the topic captures the attention of the resident doctors and the University must play a key role in this fundamental information process.

### How are Social Stereotypes Affected by the Assisted Reproductive Process in an Artificial Uterus During the Covid-19 Pandemic Period?

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Assisted reproduction in an artificial uterus is a major concern for modern society. The latest assisted reproduction experiments in an artificial matrix with experimental animals provide new data that will affect how our species spreads.

Advances in biotechnology now offer man the opportunity to intervene decisively in nature. Such interventions, however, raise relentless medical biological biotechnological, legal, religious, economic, social and political issues that require clear answers.

We have a society that is failing to adapt due to the speed of technological advances, and rapid developments will create huge ethical issues, especially in a pandemic.

In my presentation I will build on the theory of Utilitarianism (practical utilitarianism) and look at the ways in which the use of the artificial uterus in humans could be described as morally correct if it only leads to maximizing the benefit for most people even when during the Covid-19 pandemic.

The question is in a period of pandemic, can these issues that are directly related to human health but especially to safety, social stratification (position), prevailing perceptions, traditional institutions and timeless values be overcome? Also, to what extent can the issues of autonomy and personal data that take place in a pandemic period be overcome? Is the opposite view of strong desire enough to respect each person's choice for self-management, self-disposition (single parent family) or for the joint decision between the couple (heterosexual or homosexual)? Can we be open to alternative forms of family relationships? Are there limits to the desire and choice of each individual, especially in a period of health crisis - Pandemic?

I will conclude that in the ethical evaluation of assisted reproduction in an artificial womb during a pandemic, the results and the related difficulties but also what determines the moral quality of an action, that is, what determines whether something is right or wrong, are the consequences of.

**Keywords:** artificial reproduction, artificial uterus, human rights, will, moral, individual responsibility, society, social responsibility, Pandemic, health crisis, autonomy, self-determination, self-management, personal data, purpose, consequences

## The Wish to Die in Stroke Survivors in Southeast Serbia

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Wish to die is described in stroke survivors with severe disabilities. However, its prevalence is strongly influenced by cultural background. The aim of this study was to determine the prevalence of suicidal ideation and wish to die in stroke survivors in Serbia.

Our sample included 2198 patients with ischemic stroke and intracerebral hemorrhage who were hospitalized at the Clinic of Neurology in Niš (Serbia). Patients with aphasia, dementia, and those who declined testing were excluded. We have used the Mini-mental state examination and the Geriatric depression scale to assess cognitive impairments and depression symptoms. Patients were interviewed about suicidal ideation and wish to die.

Our results showed that on discharge ( $8 \pm 3.7$  days after stroke onset) 66.97% of assessed patients were diagnosed with post-stroke depression, while 3.59% of patients expressed suicidal ideation and wish to die. No patients asked for euthanasia. On the follow up ( $95 \pm 27$  days after stroke onset) 51.5% of assessed patients were diagnosed with post-stroke depression, while 1.68% of those patients expressed suicidal ideation and wish to die. Again, no patients asked for euthanasia.

Post-stroke depression is a frequent disorder in stroke survivors. However, a small number of patients showed consistent suicidal ideation and wish to die.

## Examining the Clarity of a Patient Informed Consent Form

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Patient's consent to a procedure is an expression of intent and determines the scope and method of doctor's intervention. A consent constitutes a condition for the legality of actions. It is extremely important that consent is to be given consciously. Therefore, a patient has to be properly informed to be able to understand the consequences of one's decision fully.

**Methodology:** The purpose of the study was to determine the clarity of a prepared form of patient consent. At an initial stage, a form was prepared that met the requirements of Polish laws and case-law. Next, the study of its clarity was carried out. A group of about 100 volunteers was selected for the study, from different age groups, who were not professionally involved in working with documentation. Next, a study was conducted using an application that assessed the level of text comprehensibility with a 7-level scale: 1 – a very simple text, 7 – a very complicated professional text. **Findings:** The form prepared according to legal requirements was found to be written in an excessively refined language. It required a number of stylistic adaptations, such as: the replacement of a long sentence with a shorter one, shortening sentences by eliminating redundant words, replacing difficult words with simpler ones, and using personalized forms. **Conclusions:** Creating a form of patient consent requires legal knowledge, but in the process of its drawing up one should use tools that enable to assess its clarity.



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