



STUDIA UNIVERSITATIS
BABEŞ-BOLYAI

37th Annual Conference of the
European Association of Centres of Medical Ethics (EACME)
SMART ETHICS. TRENDS TO THE FUTURE



BIOETHICA

Special Issue/2021

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UNIVERSITATIS BABEȘ-BOLYAI
BIOETHICA**

**37th Annual Conference of the European
Association of Centres of Medical Ethics
(EACME)**

**SMART ETHICS.
TRENDS TO THE FUTURE**

**September 9-11, 2021
Cluj-Napoca, Romania**

**Special Issue
2021**

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Welcome Letter

On behalf of the planning committee of the Annual EACME Conference, it is my pleasure to welcome you in Cluj-Napoca, the heart of Transylvania! This is the 37th Annual Conference on Medical Ethics and Bioethics, held for the first time in Romania and after 27 years in one of the East European countries.

This year EACME is organized by Iuliu Hațieganu University of Medicine and Pharmacy in partnership with the Babes-Bolyai University.

The theme – *Smart Ethics. Trends to the Future*, chosen for 2020 EACME conference – has been very attractive, especial in the actual international context.

Due to the COVID-19 pandemic the 2020 annual conference was postponed, to figure out how to organize such event, but even keep participants and organizers safe from possible infections.

And now, for the first time in history, we will be offering participants the flexibility to choose between attending the conference venue physically, and joining the event virtually through the online events platform.

167 abstracts have been submitted, 120 have been confirmed, 26 countries from 3 continents are represented, 4 plenary sessions and 32 scientific sessions will present a wide selection of distinguished speakers.

A day before the Conference start, on September 8, 2021, we also have two satellites meetings: European Clinical Ethics Network (ECEN)'s 7th Open Forum Day, online: Ethical Expertise: *What do we need in Clinical Ethics Support?*; and Cambridge Consortium of Bioethics Education (Cambridge Network) Satellite Meeting, hybrid.

WELCOME LETTER

We hope that the 37th EACME Annual Conference will increase the interest in Medical Ethics, Bioethics, Integrity in Research and will offer the opportunity to enjoy the this unique experience on joining Cluj-Napoca EACME Conference from everywhere.

Maria Aluș

On behalf of the Conference Organizing Committee

2021 EACME Conference – *Smart Ethics in Transylvania*

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS – GENERAL INFORMATION –

EACME, in full the European Association of Centres of Medical Ethics, was founded in the early 1980s by a small group of theologians, philosophers and medical doctors who were involved in the new discipline of medical ethics or, as it is now often called, bioethics. These so-called 'founding fathers', had the intention to create a network of centres of medical ethics in Europe with the purpose to strengthen the teaching, research, communication and debate on ethical issues in medical practice, health policy and medical sciences.

The official starting date of EACME is the 2nd of December 1986 when representatives of six centres came together in Lyon to create this new organisation. The centres (including the Bulletin of Medical Ethics) were located in France (Lyon, Paris), Spain (Barcelona), Belgium (Brussels), the Netherlands (Maastricht) and the United Kingdom (London). The strong presence of clergymen on the original Board was the reason why the EACME has stressed from the start its pluralist approach to bioethical issues.

The association expanded in the nineties, when bioethics centres in Europe were increasingly cooperating in research and teaching projects funded by the European Commission.

This development was the background for the professionalisation of the young association, strengthened by an efficient organisation and administration under the guidance of the EACME Board and Bureau. New centres joined the organisation, from all over the European continent, stimulating and strengthening the pluralist character of EACME.

Currently, about 60 centres are members of EACME, including associate members. The most important activity of EACME is the Annual Conference, organised by one of its members with support by the members of the Bureau. The conference presents an open platform for research contributions and

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS
– GENERAL INFORMATION –

debate about ethical issues in health care practices, policies, and biomedical sciences as well as new approaches in clinical ethics, research ethics and ethics teaching.

While in the early days EACME conferences were in general meetings for senior bioethicists, the current annual conferences of EACME are offering opportunities for both senior and junior researchers to present their work to a broad international audience. The EACME specifically encourages collaboration between its member centres and offers an Exchange Programme and Collaboration Prize. To conclude, EACME has developed from a relatively closed meeting space for pioneer bioethicists towards an open and vibrant community for senior and junior researchers with the aim to develop and strengthen the discipline of bioethics in the European context.

Source: EACME website: <https://eacmeweb.com/>

PLENARY SESSIONS

KEY NOTE SPEAKER: GUIDO DE WERT

Guido de Wert, ethicist, is professor of Biomedical Ethics at the Faculty of Health, Medicine and Life Sciences, at Maastricht University, The Netherlands. He chaired the Faculty's Department 'Health, Ethics & Society' from 2009-2019. His main research interests regard the ethics of genomic, reproductive and regenerative medicine. Guido de Wert was a Crown-appointed member of the Health Council of the Netherlands for many years. He is a member of both the Professional and Public Policy Committee (PPPC) of the European Society of Human Genetics (ESHG) and the Ethics Committee of the European Society of Human Reproduction and Embryology (ESHRE), and co-authored a whole series of Opinions and Recommendations of these European Societies.

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GUIDO DE WERT

HUMAN GERMLINE GENOME EDITING: CURSE OR BLESSING?

Plenary Session III

Technological developments in genome editing raise high expectations for clinical applications, also for germline genome editing (GGE). Clinical (reproductive) GGE is currently categorically prohibited in many countries, in line with relevant European regulations.

What are the arguments behind this prohibitive legislation - and are they convincing? If a technique could help to avoid serious genetic disorders in future children in a safe and effective way, would this be a reason to reconsider a categorical prohibition? Taking account of both deontological and (different types of) consequentialist ethical arguments, it is argued that:

- both basic and preclinical research regarding GGE can be morally justified on conditions;

- while clinical GGE would be totally premature, it might become a responsible intervention in the future, both as an add-on to and an alternative for preimplantation genetic testing (PGT) for genetic conditions, but only after adequate pre-clinical research suggesting that GGE is sufficiently safe and effective;
- the categorical prohibition of clinical GGE needs critical discussion, also at a European level;
- a strict regulation of clinical GGE is warranted given the relevant safety and societal concerns about unsound applications.

KEY NOTE SPEAKER: MARIANNA GENSABELLA FURNARI

Professor **Marianna Gensabella Furnari** is full Professor of Moral Philosophy at the Department of Ancient and Modern Civilizations, University of Messina. She is member of the Italian National Committee for Bioethics since 2007 to present. She teaches Bioethics, Ethics of Communication and Bioethics and Media at the Department of Ancient and Modern Civilizations, University of Messina. She also teaches Bioethics in the Course of Forensic Medicine for the Degree in Medicine and Surgery. She is also a member of the executive committee of the School of Bioethics at the San Tommaso theological institute in Messina.
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THE COVID-19 PANDEMIC AND THE BIOETHICS OF CARE

Plenary Session II

The lecture illustrates how three fundamental dimensions of the human condition (vulnerability, interdependence, uncertainty), highlighted by the pandemic, are also at the root of the bioethics of care. In the first model proposed by Warren T. Reich, the bioethics of care is, in fact, based on Heidegger's concept of Care and its link with vulnerability. It is proposed that two fundamental principles that remain implicit in the bioethics of care derive from this link: the principle of responsibility and the principle of solidarity.

In the first part of the lecture, the theme-problem of *preparedness* is viewed in light of the principle of responsibility. Dwelling on Hans Jonas's ideas on responsibility, I examine the duty of fore-seeing and its implications: the heuristics of fear, the difficulty of the shift from individual to collective responsibility, ultimately opposing the parental paradigm of responsibility proposed by Jonas with the paradigm of fraternity.

In the second part, the relationship of interdependence between individual health and public health is examined, highlighting the marked inequalities that remain. Starting with some reflections on the principle of solidarity and its

relationship with responsibility, the shift from the “fact” of interdependence to the ethical principle of solidarity is retraced, also through the rereading of an opinion issued by Italy’s National Bioethics Council (CNB) in 2020.

This shift is seen in conclusion as both utopian and necessary if we are to re-interpret the pandemic emergency as a crisis that may result in a new beginning.

KEY NOTE SPEAKER: ROSAMOND RHODES

Rosamond Rhodes, Ph.D., is Professor of Medical Education and Director of Bioethics Education at Icahn School of Medicine at Mount Sinai, Professor of Philosophy at The Graduate Center, CUNY, and Professor of Bioethics and Associate Director of the Clarkson-Mount Sinai Bioethics Program. She writes on a broad array of issues in bioethics and has published 225 articles and chapters. She is co-editor of *The Human Microbiome: Ethical, Legal and Social Concerns* (Oxford University Press, 2013), *The Blackwell Guide to Medical Ethics* (Blackwell, 2007), *Medicine and Social Justice: Essays on the Distribution of Health Care* (Oxford University Press, first edition 2002; second edition 2012), *Physician Assisted Suicide: Expanding the Debate* (Routledge, 1998). Her forthcoming book is *The Trusted Doctor: Medical Ethics and Professionalism*, which is to be released in January 2020 by Oxford University Press.
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MEDICAL ETHICS: UNCOMMON MORALITY AND THE IMPLICATIONS FOR MEDICAL ETHICS EDUCATION

Plenary Session IV

Common morality has been the touchstone for addressing issues of medical ethics since the publication of Beauchamp and Childress's *Principles of Biomedical Ethics* in 1979. In my presentation, I will challenge that reigning view by presenting two arguments. The negative argument shows why common morality cannot be the ethics of medicine. The positive argument explains why medical professions require their own ethics. I will then explain medicine's distinctive ethics in terms of the trust that society allows to the profession. By distinguishing roles from professions, I will explicate sixteen specific duties that medical professionals undertake when they join the profession.

My derivation of medicine's distinctive ethics begins with a thought experiment demonstrating that trust is at the core of medical practice. Society allows doctors to develop special knowledge and skills and allows them to employ

special powers, privileges, and immunities that could be particularly dangerous to members of society. Society, therefore, has to be assured that professional's use of their remarkable powers and privileges will be constrained to their intended use. Professions' publically declared codes and oaths go a long way to engender public confidence in medical professionals. Medical education must complete the job by helping our trainees understand their professional obligations and become clinicians who uphold their profession's ethics. Medical educators therefor have to help our students comprehend and internalize their duty to "seek trust and be deserving of it," and uphold their fiduciary responsibility to "use medical knowledge, skills, powers and privileges for the benefit of patients and society."

KEY NOTE SPEAKER: JAN HELGE SOLBAKK

Jan Helge Solbakk is a medical doctor (Oslo University, 1987) and theologian (Oslo University, 1989), and he holds a PhD in Ancient Greek Philosophy (Oslo University, 1993). Since 1996, he has been Professor of medical ethics at Center for Ethics, University of Oslo. Between 1996 and 2011, he was Associate Professor of medical ethics at the Center for International Health, University of Bergen. In 2007 and 2008, he was Head of the UNESCO Bioethics Programme, UNESCO Headquarters, Paris. In the period of 2010-2013, he chaired the Ethics and Public Policies Committee of the International Society for Stem Cells Research (ISSCR). Finally, he serves as an ethics expert for various international organizations (UNESCO, the European Commission, the European and Developing Countries Clinical Trials Partnership, and the Council of Europe). Solbakk has numerous publications and has participated/is involved in various international research and capacity building projects relating to bioethics teaching, research ethics and integrity in research, research biobanking, personalised medicine, nanomedicine, and stem cell research.
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WHY GOODNESS AND INTEGRITY IN RESEARCH MATTERS, AND PERHAPS MOST

Plenary Session I

In this key note I will address four interrelated questions: What is this 'thing' called goodness? Second, what kind – or type - of goodness should we strive for in research? Third, why does goodness in research matter? Fourth, what kind of goodness matters most in research, and why? These questions will be addressed by introducing a typology of goodness making it possible to differentiate between 6 distinct types of goodness. In addition, a distinction between the *doing* and the *being* of a researcher will be made use of to answer these questions.

PARALLEL SESSIONS

ORAL PRESENTATIONS
ABSTRACTS

MATTER OVER MIND. WHAT SUPPORT FOR FAMILIES WITH INTERSEX CHILDREN EXIST?

Daria Abrosimova¹, Martin Gramc²

Presenters: Daria Abrosimova & Martin Gramc

Parallel Session IV, Room 2

The complex treatment of intersex people in medicine has for too long neglected the support for their families. Decision-making process included parental concerns and wishes, but the emotional and peer support of families with intersex people may not always be provided. We investigate access and availability of psychological and peer support for families with intersex children.

Even though the 2005 Consensus statement on DSD strongly recommended new protocol in which families should be provided psychological and peer support during decision-making process, we claim that this is still not the case. Even if there is a psychologist or psychiatrist in the multidisciplinary team during the process, that does not mean that families are provided with psychological support.

Based on the scoping review method we want to identify existing professional-peer support and intervention tools for parents with intersex children. We investigate the implementation strategies for professional psychosocial interventions and examine the literature assessing their effectiveness.

Our claim is that psychological and peer support are not fully implemented in the treatment process of intersex people, because the role of psychologist, psychiatrist or peer groups is seen as secondary in comparison to the one on surgeons within the multidisciplinary team of medical professionals. This leads to lack of psychosocial and peer support and to mental distress of families and their intersex children.

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IS THERE A MORAL INTENTION TO REPRODUCE SOMEONE ELSE?

Atanas Anov¹

Presenter: Atanas Anov

Parallel Session III, Room 1

Moral intentions could be used as criteria for actions. In medical practice, moral intentions take an interesting form when the problem is related to post-mortem reproduction.

This paper will attempt to 1) interpret the problem of intentions from principalist perspective in medical ethics; 2) relate the problem of intentions to post-mortem reproduction; 3) develop an existentialist account for intentions and post-mortem reproduction.

Peter Zhu's case is the latest ethical challenge in post-modern reproduction. Its moral sensitivity is high due to his presume intent to reproduce and the possibility for post-mortem reproduction using donors' material and a surrogate mother. If we presume that the concept of presume intent lies with the general idea for intentions, we must tackle the problem from the perspective of respect for autonomy. The problem with intentions is that the prospective intentional action to reproduce belongs to one person only. Yet it appears that someone else is going to perform this action and someone else will finish it. Who should we hold responsible for this action: the person who intended to do it or the person who is intending to perform it and finish it? In Peter Zhu's case, there are participants with different intentions that are with different moral value. The existentialist account of post-mortem reproduction and intending to reproduce will try to present why we should be careful with respect for autonomy. The ethical and existential consequences of such reproduction are that the future child would be brought to a life of suffering and vagueness.

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UNDERSTANDING RESPONSIBILITY IN STEM CELL RESEARCH

Lars Assen¹, Karin Jongma², Annelien Bredenoord³

Presenter: Lars Assen

Parallel Session III, Room 8

Over the years, numerous ethical implications in stem cell research have been identified. Consequentially, there is a need to anticipate, prevent and/or mitigate these implications. In literature and in the guidelines of the International Society for Stem Cell Research some of these implications have been reframed into (moral) responsibilities. What exactly is meant by responsibility and which notions of responsibility are important often remains unclear. As a consequence, this encumbers the possibility to deal with these responsibilities in a systematic way.

Therefore, the goal of this paper is to discuss how the concept of responsibility in stem cell research could best be understood. This paper addresses which notions of responsibility are relevant for the field of stem cell research. This will be done by first distinguishing between backward-looking and forward-looking notions of responsibilities, where backward-looking responsibilities are about reactive attitudes and forward-looking responsibilities are about what could be expected from someone to prevent ethical implications. Subsequently, ethical implications of and wrongdoings in stem cell research will be categorized in these notions of responsibility.

Taking one step back and looking at the different notions of responsibility could help to identify gaps in responsibilities as well as to distinguish obligatory and supererogatory responsibilities. Consequentially, this informs how to prioritize, distribute and delegate responsibilities over the different stakeholders in stem cell research. This paper concludes by discussing the distribution of responsibilities and different strategies to promote responsibility in stem cell research.

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iPS CELLS: DON'T FORGET ABOUT THE SOFT IMPACTS

**Lars Assen¹, Annelien Bredenoord², Karin Jongsma²,
Marianna Tryfonidou³, Rosario Isasi⁴**

Presenter: Lars Assen

Parallel Session I, Room 8

Induced pluripotent stem cells (iPSCs) have been praised for overcoming some of the ethical challenges of embryonic stem cell research, including oocyte donation for research and the destruction of human embryos. However, iPSC-research and iPSC-based interventions are not morally neutral alternatives and have their own ethical implications that are not fully understood yet. While there is some understanding of ethical issues surrounding the derivation, storage and use of human tissue, there is less understanding of how iPSC-research affects our society and morality. Consequentially, it is difficult to fully anticipate those implications.

The notion of hard and soft impacts could benefit the understanding and anticipation of ethical implications of iPSC-research and interventions. Hard impacts are those direct physical and financial effects of iPSCs that are quantifiable and measurable. So-called soft impacts have a different focus. They consider how a technology or intervention affects our psychology, societal structures, morality and our behavior, hereby influencing the uptake, effects and evaluation of technology.

So far, academic literature and researchers focus primarily on hard impacts of iPSC-research. Soft impacts are similarly important and therefore require more academic and regulatory attention.

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LARS ASSEN, ANNELIEN BREDENOORD, KARIN JONGSMA,
MARIANNA TRYFONIDOU, ROSARIO ISASI

This talk focuses upon these understudied aspects of iPSC-research and technology. The goal is to show that for researchers and ethicists it is important to become aware of the soft impacts of iPSC-research and technology. This awareness could contribute to a broader understanding of the social value of stem cell research, anticipating ethical challenges of iPSC-research and in formulating new virtues for stem cell researchers.

ETHICAL ISSUES IN THE DEACTIVATION OF TOTAL ARTIFICIAL HEART SUPPORT – A SYSTEMATIC REVIEW

**Alberto Emanuel Bacusca¹, Andreea Elena Birlescu²,
Cristina Gavriluta³, Grigore Tinica⁴, Beatrice Gabriela Ioan⁴**
Presenters: Alberto Emanuel Bacusca & Andreea Elena Birlescu

Parallel Session I, Room 4

Introduction: In the context of a relatively constant heart donation rate, the effort to satisfy the needs, has led to the development of mechanical devices that can replace the cardiac function. Estimating an annual potential of 100,000 artificial heart implants in the United States alone, there is an increased interest in these devices, which is why it is appropriate to explore the situations where its inactivation may be ethically appropriate.

Method: We performed a systematic review, which includes all the studies regarding the dilemma of artificial hearts inactivation from the beginning until 2020, published in PubMed, Embase and Scopus. The searched keywords were “totally artificial heart and ethics”; the duplicate studies and those referring to other cardiac support devices were excluded.

Results: Following the selection, 12 articles were included in the review. The conflict between the principle of discontinuity and the prohibition generated by the indispensability of the artificial heart was emphasized. The decision to inactivate the support dependent on the patient’s declared level of happiness or clinical evolution over time was reviewed. The dilemma of self-inactivation

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of artificial cardiac support as suicide versus the acceptance of death caused by the underlying heart condition, as well as the impact of total removal of the native heart were included in the ethical analysis.

Conclusions: Requests for withdrawal of TAH support are not uncommon among patients, their discontinuation being ethically acceptable when it does not serve the patient's interests, even though they may still be capable to prolong their life.

TRANSLATIONAL ETHICS: JUSTIFIED ROLES OF BIOETHICISTS WITHIN AND BEYOND LIFECYCLES OF ARTIFICIAL INTELLIGENCE SYSTEMS IN HEALTH

Kristine Bærøe¹, Torbjørn Gundersen²

Presenter: Kristine Bærøe

Parallel Session II, Room 4

Background: Artificial Intelligence (AI) systems hold great promise for the future development within a variety of sectors. At the same time, there is also great concern about harms and potential misuse of AI. Upscaling and implementing existing AI systems do already have the potential of affecting severely, and potentially irreversibly, fundamental social conditions for social interaction, professional autonomy, and political governance. Therefore, guiding principles and frameworks to support developers and governing authorities are emerging around the world to foster justified trust in AI research and innovation. Ultimately, these safeguarding institutions and mechanisms rely on human knowledge and wisdom.

Health is an area that is expected to benefit from AI based technologies aimed at promoting beneficial, accurate and effective preventive and curative interventions. Also, machine learning technologies might be used to improve the accuracy of the evidence base for cost-effective and beneficial decision-making. How can bioethicists contribute to promote beneficial AI interventions and avoid harms produced by AI technology? What would be justified roles of bioethicists in development and use of AI systems?

Method: The paper is based on literature review and philosophical reflection.

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Discussion: In this presentation, we will base our analysis on an analytical decomposition of the life cycle of AI systems into the phases of development, deployment and use.

Furthermore, we will use a framework of translational ethics proposed by Bærøe, and identify a variety of structural tasks, as well as limitations to such, for bioethicists to undertake within this emerging multifold area of experts and disciplines.

EVERYDAY ETHICAL CHALLENGES AND INFORMAL ETHICS SUPPORT STRUCTURES OF MIGRANT CAREGIVERS IN OLDER ADULT CARE IN ENGLAND

Kumeri Bandara¹

Presenter: Kumeri Bandara

Parallel Session I, Room 3

This paper builds on anthropological fieldwork I conducted in 2019 while living for over two months with migrant caregivers of older adults in Epsom, England. Caregivers' experiences resonated with existing literature on everyday ethical challenges in caregiving: navigating divergent perspectives on good care, negotiating professional disagreements on treatments, dealing with older adults' verbal and physical abuse appropriately, and telling older adults 'white lies' to avoid mental distress. Caregivers also faced unique ethical challenges because of their migrant identities: dealing with racism, conscientious objecting of certain requests made by older adults, struggling with language when following training and defending themselves against exploitative managers, and carrying the burden of being a translator to fellow migrant colleagues.

Based on insight into ethical challenges unique to migrant caregivers, this paper focuses on informal ethics support systems on which migrants relied – an unexplored area in the literature on ethics support within social care – and explores formal ethics support systems that could support migrant caregivers in the future. Existing literature shows that the UK in general lacks ethics support systems to help caregivers recognize and appropriately address ethical challenges. The literature goes on to explore kinds of formal ethics support systems that could address ethical challenges. However, the literature completely overlooks needs and challenges unique to migrant caregivers who increasingly constitute the older adult care workforce in the UK.

Understanding everyday ethical challenges and informal support systems of migrant caregivers are important steps in ensuring wellbeing of caregivers, and thus, quality of care.

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TRANSLATING RESEARCHERS' EXPERIENCES INTO TRAINING ON RESEARCH INTEGRITY AT UNIVERSITIES OF APPLIED SCIENCES (TETRIAS)

Susan Berentsen¹, Fenneke Blom², Rob van der Sande³

Presenters: Susan Berentsen & Fenneke Blom

Parallel Session I, Room 5

In the Dutch Universities of Applied Sciences (UASs) applied research is gaining an increasingly important place in their activities, not only as a means to improve teaching but as a means to develop innovations and professionalism as well. The establishment of a clear framework of research integrity is an important condition to foster the research environment. Up to now, in the UASs there is no specific training for researchers that helps researchers to develop the necessary competencies. This project seeks to address this issue by developing a training program on 'Responsible Conduct of Research'. To identify what topics should be covered twelve researchers from six different UASs and seven different domains were interviewed (Economics, Arts and Culture, Pedagogy, Technology, Healthcare, Business Administration, and Bioinformatics). Their input resulted in a picture of the state of the art in integrity issues that the interviewees considered as important. Based on an explorative qualitative data analysis and the project team's expertise tailored learning objectives and appropriate learning methods were formulated.

The training program will likely be offered through the Association of UASs (Vereniging van Hogescholen) to all UASs in our country.

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PUBLICO – A DIGITAL TOOL FOR PANDEMIC CRISIS COMMUNICATION AND MANAGEMENT

**Nikola Biller-Andorno¹, Giovanni Spitale², Bettina Schwind²,
Kristen Jafflin³, Andrea Kaiser-Grolimund⁴, Sonja Merten³**

Presenter: Nikola Biller-Andorno

Parallel Session I, Room 7

COVID-19 vividly demonstrates the global challenges of crisis communication. A flood of pandemic-related information from various sources and highly variable quality is inundating media platforms. To counter this “infodemic”, providing high-quality information is not sufficient. Real-time feedback loops from the public to policy-makers are urgently needed to better align communication strategies, actions taken, and public perception. To achieve this, the PubliCo online platform was launched in November 2020 in Switzerland. It follows a transdisciplinary multi-stakeholder approach rooted in participatory citizen science.

PubliCo (<https://publico.community/en/>) includes three parts: 1. PubliCo Survey, collecting quantitative data, e.g. on moral preferences, while feeding back contextualized, tailored information to users; 2. PubliCo Diaries, collecting in-depth qualitative data, which also informs efforts to adapt PubliCo Survey to the evolving situation; and 3. PubliCo Analytics, which allows policymakers and other platform users to continuously analyse the collected data. We will present the PubliCo concept, considering the following key points:

1. Ethical considerations in the development of PubliCo concerning citizen science and crisis management.

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2. PubliCo as a practical tool to implement the procedural ethics concepts such as Accountability for Reasonableness.

3. Lessons learned challenges, and opportunities for the transferability of PubliCo to better manage future crises in different global contexts.

With our contribution, we aim to simulate a discussion on the ethical aspects of crisis communication and the strengths and limitations of citizen participation.

THEORISING AND CRITIQUING ‘BEST INTERESTS’: A SYSTEMATIC REVIEW

Giles Birchley¹

Presenter: Giles Birchley

Parallel Session I, Room 1

The ‘best interests’ standard is a key part of international law and bioethics, governing the medical treatment of children and adults who lack decision-making capacity. While the concept is used in various circumstances, ‘best interests’ has a long association with medical decision-making, appearing in English language medical journals from at least the early-19th century.

Despite its history, the concept of ‘best interests’ has been fiercely criticised within bioethics and law. Critics argue that ‘best interests’ is vague and lacks specificity, and because of this, is an unchallengeable repository of medical power, and an affront to patient autonomy or parental rights. These critiques have fuelled recent calls to replace or radically reform the ‘best interests’ standard from international bodies (the Committee on the Rights of Persons with Disabilities), and national campaign groups (the Charlie Gard Foundation in the United Kingdom).

This paper, undertaken as part the BABEL Wellcome Trust Collaborative Award, presents a systematic review of fifty-three theoretically rich analyses of best interests from the 1970s to the present. The discussions consider best interests primarily in clinical situations, such as withdrawal of treatment, dementia, organ donation and circumcision. They reveal a range of theories that underlie best interests including objectivism, paternalism, patient rights, pragmatism and utilitarianism. We discuss what this multiplicity of theoretical bases can reveal about the coherence of current critiques as well as the fundamental structure, and prospects of survival, of the ‘best interests’ standard.

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A SMART ETHICS IS AN ETHICS COMMITTED TO CLOSE-LISTENING

Bernadette Blesgraaf-Roest¹

Presenter: Bernadette Blesgraaf-Roest

Parallel Session II, Room 1

A 'smart' bioethics is an ethics that is able to recognize and address the real-life and context-embedded moral concerns of the people it intends to serve, whether those people are patients, relatives, healthcare professionals, researchers or policy-makers. Therefore, close-listening to what those people have to say, should be at the start of each bioethics-undertaking.

In this presentation, I will explore how narrative approaches taken from the humanities and social sciences could help bioethicists in the 21st century to attune to and examine both the stories of others and the stories we create ourselves in medicine and bioethics. I will discuss why this is an essential first step before we embark on the normative task of bioethics, and how it entails a scrutinization of epistemological and meta-ethical positions.

Following, I will use my own research project –an empirical-ethical exploration of physician-assisted dying in Dutch general practice– as an example of how narrative approaches used in empirical research, training of researchers and normative evaluation may change one's perspective on a highly contested bioethical issue.

Last, I will discuss the question whether concepts such as narrative humility and epistemic (in)justice could and should receive more attention in bioethics-training and-research.

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THE GOOD, THE BAD AND THE UGLY IN APP DIAGNOSIS: OUTCOMES AND IMPLICATIONS BY EXAMPLE

Sorana D. Bolboacă¹, Adriana Elena Bulboacă²

Presenter: Sorana D. Bolboacă

Parallel Session II, Room 3

The Clinical Decision Support (CDS), a form of artificial intelligence (AI), consider physician expertise and cognitive function along with patient's data as the input and case-specific medical decision as an output. The improvements in physician's performances when using a CDS ranges from 13% to 68%.

The AI applications are of large interest nowadays, and a lot of effort is also put in the development of IT applications in healthcare. Medical decision support systems for non-medical staff users (MDSS-NMSF) as phone applications are nowadays available on the market. A MDSS-NMSF app is generally not accompanied by a scientific evaluation of the performances, even if they are freely available or not.

Two clinical scenarios were created, and Doctor31 retrieved the diagnosis decisions. First scenario: man, 29 years old, and three symptoms: dysphagia, weight loss (normal body mass index), and tiredness. Second scenario: women, 47 years old with L5-S1 disk herniation, abnormal anti-TPO antibodies, lower back pain (burning sensations), constipation, and tiredness.

The outcome possible effects and implications, as well as vulnerabilities induced on the used, are highlighted and discussed.

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ADVANCE CARE PLANNING AND SHARED DECISION-MAKING: PAVING THE WAY

**Francesca Bosisio¹, Daniela Ritzenthaler², Eve Rubli Truchard²,
Ralf J. Jox²**

Presenter: Francesca Bosisio

Parallel Session I, Room 3

Advance care planning (ACP) has become widely used in medical care in order to plan ahead of a loss of decision-making capacity. Since ACP aim is to promote anticipatory and substitute autonomy by engaging people – and possibly their relatives – in deciding about future goals of care and treatments, scientific literature in this field often posits that ACP involve shared decision-making. This assumption however is rarely backed up by an in-depth reflection on how shared decision-making might operate within ACP and which shared decision-making template is more likely to foster ACP.

Our ACP tool, based on a model created at the Zurich University Hospital (Krones et al, 2019), engages patients in a structured communicational process about their values and preferences for care. In this tool, ACP facilitators help patients set goals of care and document treatments decisions in three paradigmatic situations of loss of decision-making capacity. Because our ACP tool entails discussions about goals of care, quality of life, and options in terms of disease- or symptom-management, we turned to Elwyn and al.'s three talk's model (2012) and Vermunt et al.'s three level goal model (2018) in order to incorporate elements of shared decision-making in our ACP tool.

In this presentation we discuss how these models might be combined in order to foster shared decision-making within our ACP tool and, by then, broaden its scope and eventually improve its effectiveness, strengthen its theoretical foundations and uphold the ethics of care in the event of a loss of decision-making capacity.

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EGG DONATION IN ART. LEGAL AND LOGICAL ARGUMENTS

Emma Capulli¹, Elvira Passaro²

Presenter: Emma Capulli

Parallel session III, Room 1

The procuring of eggs and compensatory measures for donors today present unresolved ethical and conceptual issues, which fuel the growth of the assisted reproductive technology (ART) industry.

The speech proposes a problematization of the phenomenon from a legal point of view, supported by a rhetorical-argumentative analysis of the legal institutions.

The legal provision of oocytes admits the only donation. It was deduced by analogy from the legislative provisions of available of organs and tissues (law no. 458 of 1967; law no. 301 of 1993; law no. 91 of 1999; law no. 483 of 1999), which provides for the balance between impairment of the psycho-physical sphere and goods that benefit from it. Is this balance comparable to the available of oocytes? Or does it need an autonomous redefinition? The various national regulations show that in Europe the term donation includes not only solutions of substantial gratuity, but also various forms of compensation.

On one side this shows the fragility of the definition of donation, rhetorically constructed through the Aristotelian argument of the dissociation between reimbursement and remuneration, and on the other it makes clear the need to use logical-argumentative tools to disclose the criterion of hierarchization of values in game.

It remains to be understood how ethical reflection, led by an argumentative legal analysis, can provide the tools to improve the functioning of a system that seems to render donors' rights unfit for use.

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CLINICAL TRIALS INVOLVING MINORS: THE ROLE OF THE ETHICS CONSULTATION IN AVOIDING THERAPEUTIC MISCONCEPTION

Silvia Ceruti¹

Presenter: Silvia Ceruti

Parallel Session IV, Room 4

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.

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CLINICAL ETHICS AND DISORDER OF CONSCIOUSNESS

Chiara-Camilla Derchi¹, Silvia Ceruti², Ilaria Giubbilo³

Presenters: Ceruti Silvia & Chiara Camilla Derchi

Parallel Session IV, Room 6

Disorders of Consciousness (DOCs) identify a diverse group of dysfunctions affecting individuals who have survived severe brain damage.

Although the clinical evaluation of patients with DOC normally depends on their residual ability to create a connection with the outside world through motor behavior, in the last ten years neuroscientists have made a great effort to better characterize the patient's consciousness even in the case of reduced or no motor reactivity. Often, in fact, patients with DOCs are not able to perform any type of movement or adequately understand the command required but they might be still conscious or at least minimally conscious.

The gap between patients' motor capability and their residual brain complexity raises important moral issues, especially about appropriateness and proportionality of interventions and treatments.

We argue that Clinical Ethics Consultation may be crucial in addressing these clinical scenarios, which assume aspects of further drama when the DOC derives from a sudden and unexpected acute event such as a trauma or a cerebrovascular accident in healthy patients.

In these situations, given the particular vulnerability of the patients and the unpredictability of the diseases, Ethics Consultants should be involved in the therapeutic process in order to improve the standard of care, ensuring compliance with the inclinations and desires of the patients. Moreover, Ethics Consultants should monitor that the procedures are rigorously managed in the context of fully understood consent of those who are legally entitled to make decision.

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THE COMPARATIVE EFFECTIVENESS OF SYNCHRONOUS AND ASYNCHRONOUS ONLINE BIOETHICS LECTURE DELIVERY ON STUDENT LEARNING IN DISCUSSION BOARD POSTS

**Jenny Clark Schiff¹, Michael L. J. Greer², Ryan Felder³,
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Presenters: Jenny Clark Schiff & Michael L. J. Greer

Parallel Session I, Room 6

Due to the COVID-19 pandemic, many courses that were once in person are now online. In our new “physically distanced” world, bioethics faculty has had to adapt quickly. To bridge the gap created by eliminating face-to-face interaction for two cohorts of international bioethics students, we combined them and created five four-week online bioethics mini-courses: “Justice and Pandemic Diseases,” “Reproduction,” “Pediatrics,” “Organ Transplantation,” and “Death and Dying.” Each mini-course involved required readings, weekly lectures, discussion board participation, and a final paper. Our study evaluates the comparative effectiveness of synchronous and asynchronous lecture delivery on student learning as evidenced in online discussion board posts in the mini-courses.

Students from both cohorts received the same educational materials but were divided into two groups for alternating synchronous and asynchronous Zoom lectures. We developed a standardized rubric, and raters have been using it to

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score each student's initial posts. We hypothesized that, for the same discussion board question, students' scores on posts following synchronous lectures will on average be higher than those following asynchronous lectures. We will finalize our data analysis at the conclusion of the final mini-course in late March and learn if the data support our hypothesis.

There are many challenges in determining the comparative effectiveness of synchronous and asynchronous teaching on overall student learning. Our study addresses a modest yet worthwhile question, whether and to what degree these different lecture modalities impact student learning evidenced in discussion board posts. Our findings will contribute to bioethics pedagogical research during these challenging times.

WHAT ETHICS FOR AN INCLUSIVE AGEING SOCIETY?

Jean-Philippe Cobbaut¹, Grégory Aiguier²

Presenter : Jean-Philippe Cobbaut

Parallel Session I, Room 3

Context: the ageing of the population today raises a significant number of questions to stakeholders in the health and social sectors. These questions go far beyond the questions of care to stretch out to a series of ethical problems linked to lifestyle and thus to the management of projects dedicated to the support and social inclusion of the elderly.

Purpose: in this context, the way of considering the treatment of the ethical dimensions of these projects requires collaborative and reflexive governance based on the articulation between clinical ethics, organizational ethics but also – increasingly – an ethical approach of social and territorial deployment of these projects with the various stakeholders.

Method: this communication will aim to present the results of two research-action studies aimed at the development and the integration of the ethical dimension in collective projects of accompaniment of elderly people within the community.

Results: the conclusions do reflect the need for the collaborative and reflexive nature of the governance of the ethical approach, by emphasizing the modalities of the participation of the people concerned and the crucial stake of taking their point of view into account. of view for a relevant approach to ethics of ageing.

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ETHICAL APPROACH TO ROAD TRAFFIC INJURIES PREVENTION

Svetlana Cociu¹

Presenter: Svetlana Cociu

Parallel Session III, Room 7

Road traffic injuries are widespread public health problem, particularly in low- and middle-income countries, being the leading cause of death for children and young adults aged 5–29 years. Road injury ranks 8th after the main causes of death, and unless there will not be a complex approach to prevention those will rank 5th by 2030.

The Republic of Moldova is characterized by a high mortality due to road crashes, children and adults over 50 years are more prone to injury or a road crashes and the age group 15-39 years there is a higher risk of death as driver or passenger in a transport unit. Road traffic injuries can be prevented, and many government interventions, policies and programs have been proposed in order to prevent road injuries, but their prevention was less approached by applying and respecting ethical aspects among all the participants in traffic. Each one involved in the road traffic can contribute in improving the road safety by his/her responsibility, which refers to consciousness, morality, ethics and ethical behavior, culture. Drivers and pedestrian have the moral duty while driving to use seat belt, comply with road traffic rules and safety requirements and have duty not to harm- to avoid putting themselves and others in danger.

We need much more understandings of the behavior risk factors, increasing psychological capacity and benefits, investing in educational campaigns, effective communication, social support, and encouragement, increase awareness of responsibility in traffic and increasing respect for all participants in traffic, without causing any harm.

Acknowledgement: Rosamond Rhodes, Ph.D., Professor of Medical Education, Director of Bioethics Education, Icahn School of Medicine at Mount Sinai, New York, USA.

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LIFE QUALITY OF PATIENTS WITH FACE TRANSPLANT

Vlad Covrig¹, Cristian Budacu¹, Beatrice Ioan¹

Presenter: Vlad Covrig

Parallel Session IV, Room 2

The face is the feature which best distinguishes a person, the shape of it being influenced by the bone-structure of the skull. Facial trauma, known as maxillofacial trauma, is any physical trauma to the face that can involve soft and hard tissue having the potential to cause disfigurement. The last resort solution after major facial trauma, when conventional reconstruction techniques have failed is now represented by face transplant.

The aim of this paper is to underline the life quality and psychological implication of patients that were face transplanted. Our material and method involved studying the most relevant medical literature for this issue and also using our personal experience of patient with face cancer that underwent radical oncological surgery followed by reconstruction.

Based on these data we can conclude that face transplantation appears to decrease depression and to improve patient's quality of life and societal reintegration. Also, in our opinion a very important factor involving the success of face transplantation is represented by the psychological outcomes of the patients, their follow up for a minimum 6 months period with regular psychological counselling sessions being very important.

Furthermore, there is a critical need for modification of existing rating scales to allow effective assessment of face transplant candidates before and after transplantation.

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GHOSTWRITING AND AUTHORSHIP PRACTICES IN BIOMEDICAL RESEARCH: A STUDY PROTOCOL

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Presenter: Alina-Georgiana Cozma

Parallel Session I, Room 4

Background: Scientific paper authorship represents an important form of academic attainment for research professionals and brings specific benefits (e.g., contribution science, recognizing the author's intellectual efforts). Authors certify their work's integrity by accepting the responsibility of the published content. The principal two important unethical authorship is *honorary authors* (the criteria of authorship not met) and *ghost authors* (contributed substantially but not listed as an author).

Aim: The current study has two-fold aim: to determine the prevalence of authorship violations in the biomedical journals according to the Web of Science classification and to evaluate its variation by article type (e.g., research, review, or editorial) and presence/absence authors contributions requirements.

Materials and Methods: The following steps will be apply: 1) Identification of journal categories of interest – data source: Journal Citation Reports 2020 (JCR2020); 2) Identification of the eligible journal – JCR2020 by selection of journals weighted according to the number of journals in a specific category. The selection will be stratified by the Rank by Journal Citation Indicator (JCI); 3) Collection of characteristics of the included journals regarding the year 2020: total number of articles, number of articles and references, number of reviews and associated references; JCI percentile, open access policy and publication

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fee if applicable; 4) Random selection (simple random method) of authors who published in 2020. The selection will be done weighted according to the number of manuscripts published in 2020; 5) Development and validation of the questionnaire; 6) Invitation of the corresponding author to participate in the study; 7) Online anonymously data collection. The study protocol will be deposited in an international database.

COVID-19 MENTAL HEALTH IMPACTS. CHALLENGES FOR PSYCHIATRISTS

Cătălina Crișan¹, Bianca Suci²

Presenter: Cătălina Crișan

Parallel Session III, Room 4

COVID19 a new appeared virus determined a major impact worldwide on economic and social aspects and also on the mental state level. All countries are confronting with different behaviors of coping mechanism in particular buying excessive amounts of food, being more suspicious even with the family members, explained by an exacerbated surviving instinct, making stocks of unnecessary disinfectant sanitary products, even a chase for protective masks in some cases. Some of these aspects can be considered the effect of a mass psychosis, people being misinformed by television news, such as the concept of fake news having the intention of manipulation; others misinterpret the clear message, with severe consequences over the state of calm. During this crisis, all psychiatrists are facing new challenges such as sustaining the well-being of healthcare personnel, looking over the need of patient's mental well-being, taking care of the psychological impact of quarantine, self-isolation and social stigma associated with COVID 19.

An important aspect in Romania is represented by different cultural beliefs that are not usually present in other cultures but are characteristic in our population and can influence the outcome of the virus evolution. Protection from God, believing that spirituality and religiosity can become a fence in the confrontation with the virus, and these convictions could become a real impediment in understating and respecting the protocols and the rules of prevention.

The ethical issue for psychiatrists is how to take into account patients' beliefs in time of restrictive measures imposed by COVID19 pandemic? All in all, the COVID19 pandemic spread represents a real challenge for all employees in the medical system, but especially to psychiatrists, who should deal with patients whose capacity to understand the real/whole picture is deteriorated.

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COULD COVID-19 CHALLENGE TRIALS BE REASONABLY REJECTED AS MORALLY IMPERMISSIBLE? A CONTRACTUALIST PERSPECTIVE

Horațiu Traian Crișan¹

Presenter: Horațiu Traian Crișan

Parallel Session IV, Room 5

In challenge experiments, research subjects are exposed to a pathogen agent in order to study a certain disease, and/or to determine the amount of infecting dosage, and/or to test the efficacy of a vaccine.

General discussions on challenge experiments have already been undertaken in contemporary medical research and these uptakes generate an ongoing debate about their ethical permissibility. Recently, these research issues have focused also on Covid-19 challenge trials in which the determination of the infecting dosage, the efficacy test of vaccines and the immune response of people who already passed through the disease have been investigated.

In my paper, I will offer a philosophical perspective on these specific trials, based on T. M. Scanlon's version of contractualism. I will start by briefly presenting the features of Scanlon's contractualist ethical theory and by formulating the moral principles which could support Covid-19 challenge trials. Thereafter, I will search for reasonable rejections in order to be able to establish whether this type of trials is ethically permissible or not.

In the second part of my presentation, I will tackle Scanlon's view on medical experimentation in general and his subsequent distinction between direct harm and accidental harm, in order to argue for its relevance for the case of Covid-19 challenge trials. I will demonstrate that according to the general contractualist perspective, these trials are not ethically justifiable.

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Finally, I will search for a consolidation of my argument, by considering a tighter version of contractualism to be applied to the domain of medical research.

Research reported in this presentation was supported by Fogarty International Center of the National Institutes of Health under award number R25TW01051.

TOLERANCE: TOO LITTLE FOR CLINICAL ETHICS IN A PLURALIST SOCIETY?

Paul J. Cummins¹, Federico Nicoli²

Presenter: Paul J. Cummins

Parallel Session III, Room 5

Virtually all Western societies embrace liberalism as a political and moral; it emphasizes individual rights and liberty, democracy, autonomy, limited government, consent, pluralism, and tolerance. Clinical ethics in these societies reflects those priorities.

Human migration has made Western societies more diverse and expanded the plurality of values represented within them. As a consequence, clinical ethics consultants (CEC) have encountered cases which reflect a clash between the liberal values of contemporary medical ethics and non-liberal values of patients. Because CECs are steeped in liberalism, their default attitude toward the values outside of that tradition will be tolerance.

This paper will argue that because tolerance implicitly contains a judgment of inferiority to other values, it is the wrong attitude for CECs to adopt towards parties whose fundamental values clash with medical ethics. In such cases, this attitude can disrespect to the holders of the values, endorse a consequentialist compromise of values, and leave medical professionals prone to moral distress. Agonism democracy is a political philosophy that accepts that values conflicts are inevitable, and there will be winners and losers from them. It aims to channel this conflict positively by promoting a process marked by openness to questioning fundamental values and genuine consideration of (even contrary) alternate values. As an alternative to tolerance, this paper will explore if cultivating an attitude of agonism can be a better disposition for CECs in such cases.

It will use a case study to compare the results of the two approaches in cases of fundamental values clash.

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DOCTOR – PATIENT RELATIONSHIP IN CLINICAL LEGAL – MEDICINE PRACTICE

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Presenter: George Cristian Curca

Parallel Session IV, Room 1

Introduction. In Romania legal medicine suppose professional activities as forensic pathologist and legal doctor are facing victims that request documenting traumatic lesions if any or sexual abuses, prejudices, working capacity, malpraxis, etc.

Objective. The objective of our work is to determine the special kind of doctor-patient relationship in clinical legal medicine and to analyze the ethical influences.

Material and methods. More than 1500 cases of medico-legal examinations are performed in the National Institute of Legal Medicine Mina Minovici in Bucharest each year. Most of them are domestic violence requests or car accidents.

Discussions. In the late 30 years (Ezechiel JE, Linda LE, JAMA 1992) found out 4 different relationship models that may be applied in medical practice; the paternalistic model (the patient accepts his doctor as his legal and moral representative), informative model (the patient expresses his autonomy), interpretative model (the doctor is a good friend in need) and the deliberative model of self-construction of the knowledge that the patient must have in order to have a voluntary decision.

Conclusions. In clinical legal medicine the patient is not only a patient but a victim also. Therefore, the relationship is double folded. With his patient the legal doctor develops initially an informative model, then an interpretative

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model. With his victim the doctor develops initially a paternalistic approach (passive character type) or an informative one (active character type), usually an interpretative model as most highly requested (What would you do if you were I?) or the deliberative model when evaluating prejudices, etc.

A RESEARCH OF MEDICAL ETHICS AND BIOETHICS TOPICS AND KEYWORDS IN MAJOR DATABASES IN TWO PERIOD TIME: 1918-1919 SPANISH FLU PANDEMIC AND 2020 NOVEL CORONAVIRUS PANDEMIC – MAIN VALUES AND SOCIAL NEEDS

George Cristian Curca¹, Ruxadra Ioana Țurlea¹, Larisa Udriștioiu¹
Presenter: George Cristian Curca

Parallel Session III, Room 4

The World Health Organization (WHO) on March 11, 2020, has declared the novel coronavirus (COVID-19) outbreak a global pandemic. But in the last 130 years mankind overpassed 5 major pandemic times. We noticed that bioethics has been born at the twilight of the Tuskegee experiment in 1972-1979 the period, needed for the federal research and Belmont report issue. Therefore, Spanish flu pandemic did not benefit from bioethics insights but medical ethics and Hippocrates Oath however influenced doctor's professional ethics. We compare 1918-1919 topics of medical ethics for Spanish flu with 2020 for Coronavirus. We found out that PubMed (nih.gov) recognize some 8 issues for "medical ethics" and "Spanish flu" v. 792 for "medical ethics" and "coronavirus", this is 100 times more. Most frequent key words are researched. Also, there are researched major moral values and bioethical principles that are at stake in pandemic time in order to improve our reactivity and adaptability to such global health problems.

The question is that in Spanish flu pandemic when bioethics was not yet an important approach for diversity of values as it is now in 2020 coronavirus pandemic, society and medical system during the First World War was less prepared for ethical solutions of treatment and prevention of a pandemics disease than today. Responsibility, equity and justice must prevail for the treatment and for prevention. Ethics of scarce resources allocation brings the most complicate questions and require for a holistic approach and equity.

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ETHICAL MODELS IN THE DOUBLE RELATIONSHIP PHYSICIAN-PATIENT WHEN ESTABLISHING CHILD CUSTODY IN PARENTAL DIVORCE AND SEPARATION WITH INTENSE CONFLICTUALITY: DIFFERENT CONCEPTS FOR PHYSICIAN AND FOR PSYCHOLOGIST?

**George Cristian Curca¹, Iuliana Diac², Iuliana Dobrescu³,
Lucia-Emanuela Andrei³, Mihaela Stancu², Florina Rad², Elena
Stefanache⁴, Simona Dragomirescu⁴, Georgia Francesca Culea⁴**

Presenter: George Cristian Curca

Parallel Session II, Room 5

Introduction. Child custody judicial course usually are intense conflictual raising a lot of pressure both on adult parents as on children. Always require a forensic psychiatry set-up at the court request and a professional team, legal doctors, psychiatrists, psychologists of adult and children from the legal medicine institution and from the hospital. Children are carefully looked upon separately by psychologists in a special setu-up diregarding intruding and manipulation.

Objective of this presentation is to identify ethical aspects of the relationship physician-patient (the adult parent and separate the child) and psychologist-patient (i.e. similar) in custody litigation.

Material and methods. We have casuistry with a high diversity of parental alienation in child custody cases.

Discussions: Does physicians (psychiatrist or legal doctor) and psychologists uses different ethical models and concepts to approache the adult parent or

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the child? Forensic psychiatry examinations are completed with psychiatry examination and psychology examination as much as documents examinations which are presented in the dossier. Social inquiry is very important.

Conclusions: similar to physician-patient relationship in pediatry, psychologist-minor patient relationship is based on the same moral values and ethical principles: beneficence, nonmaleficence, justice, loyalty, trust, mostly in a paternalistic model to sustain always the best interest of the child/children. Lack of autonomy of the minor child creates correlativity obligations to protect his rights and to sustain the best interests of the child as a primary consideration. Beneficence in forensic psychiatry may take into consideration maintaining also beneficial emotional relationships with both parents after the separation.

COVID-19, THE PERFECT TIME TO BROADEN OUR HORIZONS ABOUT SOCIAL MEDIA USE IN ONCOLOGY?

Eva De Clercq¹, Michael Rost², Bernice Elger²

Presenter: Eva De Clercq

Parallel Session III, Room 4

Objective: The study aims to explore the attitudes of Swiss healthcare professionals towards the use of social media in adolescent and young adult oncology and to examine whether the ongoing social restrictions due COVID-19 might have altered these attitudes.

Methods: This study was cross-sectional in design. The subjects were healthcare providers working in pediatric or adult oncology settings in Switzerland. We performed descriptive and inferential statistical analyses.

Results: While considered useful, only a small minority of participants actually used social media for professional reasons and considered themselves skillful in using these platforms. Although institutional guidelines were deemed crucial to improve social media use, many respondents seemed unaware of their existence. Only a minority reported an impact of Covid-19 on their attitudes towards the professional implementation of social media.

Conclusion: The global health crisis creates important challenges for young patients with cancer and their healthcare providers. In times of social restrictions, social media may be promising tools to facilitate health information provision, connectivity and patient care. Virtual mentorship and target social media training interventions might be the best way to improve familiarity with social media and with ethical guidelines for their use.

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ENDING MALARIA WITH GENE DRIVE TECHNOLOGIES? A NORMATIVE ANALYSIS OF THE ROLE OF HUMANS IN NATURE

Nienke de Graeff¹, Karin Jongma², Annelien Bredenoord²

Presenter: Nienke de Graeff

Parallel Session III, Room 8

Gene drive technologies (GDT) promote the rapid, progressive spread of gene alterations within a population or a species of wild organisms. If GDT are successfully developed and implemented, they could help to resolve intractable problems in the realm of vector-borne disease, invasive species and pest control, but these technologies have also raised concerns regarding the moral permissibility of interfering in nature in this way. In particular, it has been argued that perspectives on humans' relationship to nature and their impact on and manipulation of ecosystems play a crucial role in determining the moral permissibility of GDT. Nonetheless, these perspectives have thus far remained underexplored in the emerging ethical debate on GDT.

In this presentation, I identify these perspectives and concerns and analyse them normatively. Four issues are demonstrated to be of central importance in deciding whether (a particular) use of GDT is in accordance with the relationship humans should have to nature: (1) the moral status of and direct duties towards different organisms; (2) the prioritisation of duties towards different organisms in case of conflicting claims; (3) the moral (ir)relevance of 'wildness'; and (4) the moral status of holistic entities such as species and ecosystems.

The normative positions that can be taken on these issues are presented and critically assessed to determine the moral permissibility of particular applications of GDT. Doing so elucidates the central trade-offs and points of contention in the ethical debate on interfering in nature in this way.

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USING AT-HOME DNA TESTS FOR CRIMINAL INVESTIGATIONS – A CALL FOR A COLLECTIVE APPROACH TO INVESTIGATIVE GENETIC GENEALOGY

Nina de Groot¹

Presenter: Nina de Groot

Parallel Session III, Room 2

Tens of millions of people worldwide have taken a commercial at-home DNA test out of interest in their genetic ancestry, disease risks, cilantro taste aversion, or athletic performance capacities. Yet, this consumer DNA data is also of interest to law enforcement: the data can be used to identify criminal suspects. By uploading a genetic profile from an unknown suspect, found at the crime scene, to a database with consumer's genetic data, one could find a distant relative of the suspect. Through the mapping of this relative's family tree, police can eventually zero in on the actual perpetrator. However, this investigative genetic genealogy (IGG) raises ethical concerns.

In this presentation, I aim to contribute to the bioethical analysis of IGG by exploring the limitations of an individual-based model for IGG. I discuss two ethical concerns of IGG: privacy and informed consent. However, I argue that IGG raises specific ethical challenges that extend beyond these two autonomy-related concepts. Because of the far-reaching scope to identify even very distant relatives, IGG could identify a vast majority of a target population, thus making it also a collective issue.

I explore how the ethical approach of individual consent and relatives in the biomedical genetic context can be helpful for the debate on IGG. Additional ethical concerns arise from the international, transgenerational, and commercial nature of IGG. I call for a more collective approach to IGG in the ethical debate.

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ETHICS OF FIRST-IN-HUMAN TRANSPLANTATION TRIALS OF BIOARTIFICIAL ORGANS

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Presenter: Dide de Jongh

Parallel Session III, Room 8

The most effective treatment for type 1 diabetes is transplantation of either a whole pancreas from a deceased donor or islet cells derived from multiple deceased donors. However, transplantation has 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 regenerate organs.

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 placentas and deceased donors. The clinical development of this complex product raises ethical questions for first-in-human (FIH) clinical trials. Under what conditions can bio-artificial organs safely be transplanted in humans for the first time? How can patients be selected, recruited and informed responsibly?

In this presentation, we investigate the ethical conditions for clinical trials of bio-engineered organs, focusing inter alia on study design, subject selection, risk-benefit assessment, and informed consent. We present the results of a review of the literature on the ethics of clinical trials in regenerative medicine, cell and gene therapy and transplantation, and specify existing ethical guidance in the context of FIH transplantation trials of bioartificial organs.

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We conclude that this new and innovative area at the intersection of regenerative medicine, cell and gene therapy and transplantation requires adequate consideration of the ethical issues in order to guide responsible research and clinical implementation.

HOW SMART ARE SMART MATERIALS? A CONCEPTUAL AND ETHICAL ANALYSIS

Anne-Floor J. de Kanter¹, Karin R. Jongsma², Annelien L. Bredenoord²
Presenter: Anne-Floor J. de Kanter

Parallel Session III, Room 7

Today, a person can receive a hip implant to replace a deformed, swollen hip joint or a pacemaker to sustain the beating rhythm of their heart. Thanks to Regenerative Medicine, soon, it may become possible not just to replace, but to re-grow healthy tissues after injury or disease. To this end, tissue engineers are designing ‘smart’, ‘life-like’ biomaterial implants to activate the inherent regenerative capacity of the human body. Such a smart life-like biomaterial may for example stimulate re-growth of a fresh, living heart valve after implantation in a patient’s heart.

However, the meaning of the smartness and lifelikeness of these synthetic biomaterials is conceptually unclear. Therefore, in this paper, we first aim to unravel the meaning of the terms ‘smart’ and ‘life-like’, and next, analyse what ethical and societal implications are associated with this new generation of biomaterial implants as a result.

Our conceptual analysis reveals that the biomaterials are considered ‘smart’ because they can communicate with human tissues and ‘life-like’ because they are structurally similar to these tissues. Moreover, the biomaterial artifacts are designed to integrate to a high degree with the living tissue of the human body. While these characteristics provide the biomaterials with their therapeutic potential, we argue that it complicates a) the irreversibility of the implantation process, b) questions of ownership regarding the biomaterial implant, and c) the sense of embodiment of the receiver of the implant.

Overall, timely anticipation and consideration of these ethical challenges will promote responsible development of biomaterials in Regenerative Medicine.

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ETHICS SUPPORT FOR THE DISTRIBUTION OF HOSPITAL BEDS: CO-CREATING A MAP OF VALUES AND NORMS FOR THE ALLOCATION MEETINGS

Janine de Snoo-Trimp¹, Laura Hartman², Bert Molewijk²

Presenter: Janine de Snoo-Trimp

Parallel Session II, Room 8

Background: Allocating admitted patients to their wards is increasingly put under pressure due to high bed occupancy rates. Consequently, allocation becomes morally challenging as it is confronted with potentially conflicting values like protecting teams' workload, solidarity between wards and quality of care. Furthermore, there is a continuous uncertainty regarding expected intake, discharge, available beds and personnel. An integrative ethics support project was started to help to better deal with these challenges. After identifying core moral challenges, the aim of the current project was to co-create a map of values and norms for the daily allocation meetings.

Methods: This qualitative study included observations of allocation meetings and 13 interviews. Subsequently, in five working group sessions a map of relevant values and norms was co-created with a selection of involved professionals.

Results: Findings revealed moral challenges in three so-called 'moral circles': 1) one's own team; 2) the hospital and 3) the hospital's region. A map was developed including important and agreed upon values with 14 norms for the daily allocation meetings. Additionally, formal policies were updated and a conversation method was introduced to guide discussions when there are moral challenges.

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Conclusion: The joint development of the map led to a shared and practical product for both discussions and decisions regarding bed allocation. Its development already contributed to increased awareness of and openness about moral challenges. Using the map in daily allocation meetings may further stimulate moral reflection on these challenges to support these healthcare professionals in making well-considered and value-based decisions.

MORAL COMPETENCE, MORAL TEAMWORK, MORAL ACTION – OUTCOMES OF MORAL CASE DELIBERATION IN THE EURO- MCD 2.0 FOR EVALUATING CLINICAL ETHICS SUPPORT

Janine de Snoo-Trimp¹

Presenter: Janine de Snoo-Trimp

Parallel Session I, Room 8

Background: For Moral Case Deliberation (MCD), like any form of Clinical ethics support (CES), it is important to know whether it reaches its presumed goal of supporting healthcare professionals in their ethical challenges. Evaluation is needed to gain insight in the value of MCD. Therefore, the Euro-MCD instrument was developed to assess outcomes of MCD, and has now been revised. The aim of this presentation is to present the revised Instrument: the Euro-MCD 2.0.

Methods: The revision process was an iterative dialogue in which field study findings were integrated with theoretical reflections and expert-input.

Results: The Euro-MCD 2.0 has three domains: 1) Moral Competence, 2) Moral Teamwork and 3) Moral Action. Moral Competence includes items on moral sensitivity, analytical skills and a virtuous attitude, like ‘I speak up in ethically difficult situations’. Moral Teamwork refers to open dialogue and supportive relationships, for example ‘We feel secure to share emotions in ethically difficult situations’. Moral Action includes items about moral decision-making and responsible care, like ‘We are able to explain and justify our care towards patients and their families’.

Discussion: The Euro-MCD 2.0 is shorter and more strongly substantiated by empirical data and theoretical reflections. At the conference, we will reflect on the revision process and the underlying foundations of the domains. The revised instrument helps to get insight in the MCD related outcomes for healthcare professionals in their daily practice. Our research can further improve implementation of MCD and contribute to the research field of evaluation of CES in general.

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BRAIN BANKING – BIOETHICAL IMPLICATIONS

Ioana Diaconescu¹, Sorin Hostiuc², Curcă George Cristian³

Presenter: Ioana Diaconescu

Parallel Session IV, Room 3

Novel biotechnologies like brain banking pose a challenge in neurodegenerative diseases research, being not only a step towards a better understanding for these diseases, but also from a bioethical point of view.

Brain banks collect tissue for research purposes from deceased persons suffering from neurodegenerative diseases such as Parkinson's or Alzheimer's disease. In order to improve the quality in this research field, confidentiality and a detailed informed consent are aspects that should be emphasized. Moreover, given the fact that the brain collecting takes place during an autopsy, legal aspects also play an important role, hence a legal frame is also needed. The role of the deceased's family should also be taken into account, especially when and how they can decide if the autopsy can be performed in the first place. The research participant should sign a detailed informed consent that must remain the research basis to which extent the collected data should be disclosed.

Finally, only a framework of bioethical and legal norms can improve the quality of brain banking research. A comprehensive perspective for brain banking from obtaining, processing, and storage of brain material to bioethical and legal aspects should increase the scarce sapling of brain banking.

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PHARMACOGENOMICS: ETHICAL ISSUES IN DATA MANAGEMENT

Ioana Diaconescu¹, Sorin Hostiuc²

Presenter: Ioana Diaconescu

Parallel Session I, Room 4

Pharmacogenomics uses a DNA sequence in order to create a “genetic map” that determines which drugs are the most efficient for a specific disease, in a particular patient. The needed information for developing personalized therapies needs, besides genetic data, various non-genetic factors might interfere with some mechanisms of drug action, and they should also be considered. The assumption that the genetic data is more important than any other type of non-genetic medical information may severely alter the reliability of pharmacogenomics. In order to decrease the risk for non-genetic factors to significantly alter the pharmacogenomics-related therapies, patients need to provide detailed information about them. This, however, is often not specifically sought upon by neither the patient (who sees this information as trivial when the physician interacts directly with her/his genes), nor the physician (who is often a genetics/pharmacogenetics expert, who tends to see the genetic information as supreme).

One of the main targets in data management is privacy. A lot of effort is needed to keep the data anonymous and creating a detailed informed consent to determine the patient to acknowledge the risks and the benefits of pharmacogenomics. However, proper management of data also includes obtaining all the relevant information to maximize beneficence, this being especially important in frontier techniques, such as pharmacogenomics.

The purpose of this study is to analyze the main ethical issues in data management in pharmacogenomics, with an emphasis on the way the physician-patient relationship should be developed to maximize relevant data extraction and optimize its management.

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MODIFYING NATURAL BEHAVIORAL RESPONSES BY ENFORCING ETHICAL VALUES

Jaume Duran¹

Presenter: Jaume Duran

Parallel Session II, Room 2

According to different theories about neuroscience and ethics, we want to introduce the idea that the ethical values are very good levers to conduct human responses to their perceptions. These theories are based on very currently data about science and the central nervous system explained recently by a very important neuroscientist.

In a very basic nervous system, the reptilian brain, humans can solve their fundamental interest and necessities, such as survival, breeding, community behavior... In a more complex and posterior temporary nervous system, thanks to the known limbic brain, humans have been able to solve and to respond to their emotional problems, creating the memory center of our emotions. After this second moment and as a result of the global anthropological evolution, the cortical brain allows us to think, to deploy the global intelligences and take human decisions. Thanks to these three brain levels and their neurobiological connections, humans have developed other intangible brains, able to experience the ethics, the esthetics, and the spirituality.

Our brain works as a whole. We are the result made up of more than 100.000 million connected neurons that form the brains. In some aspects, our four dimensions, the physical, the emotional, the rational and the transcendental faces act together, hand in hand. Our more ponderous decisions aren't always rational; more than 80% of them are basically emotional. So, our spiritual manners can be showed by biophysically manifestations; conscientious and unconscientious affects us equally.

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Human brain is genetically prepared to answer. Historically formed to respond, the central nervous system can be explained as the most complex organ to produce responses to multiple previous perceptions. These perceptions can be tangible or not, external or internal, consciences or not, actual or memorized.

Our point of view is that we can introduce ethical values as a non-conscientious response. Working from rational and emotional ways our ethical values, we will introduce them in our transcendental brain. All posterior relationship between the brain areas will influence the behavior response to the real perceptions that we are exposed to. So, to summarize, enforced ethical values can unconsciously modify our behavioral response.

STEREOTYPING IN ROBOTIC CARE: AN ETHICAL ANALYSIS OF VULNERABILITIES AMONG OLDER PEOPLE IN DIGITALIZED CARE SETTINGS

Niklas Ellerich-Groppe¹, Merle Weßel², Mark Schweda²

Presenter: Niklas Ellerich-Groppe

Parallel Session I, Room 4

In light of demographic aging, the change of familial care arrangements, and the lack of skilled caretakers, robotic systems are increasingly discussed as a possible solution for eldercare. Sociopsychological research indicates that the ensuing human-robot interaction involves the same social categories as human-human interaction, e.g., gender, age and ethnicity. Indeed, these categories and related stereotypical markers are even strategically used in technology development to increase the acceptance and efficiency of robotic systems. Especially in vulnerable groups such as older people, however, such stereotyping strategies can be a reason for new vulnerabilities in digitalized care settings and cause serious moral problems that need critical reflection.

In our contribution, we provide a systematic ethical analysis of stereotyping in robotic eldercare.

Starting from the conceptual distinction between agency-based and harm-based conceptions of vulnerability, we explore potential moral issues and conflicts in the implementation of stereotypical care robots for older people and detect particularly serious challenges regarding users' autonomy and wellbeing. Against this backdrop, we propose and discuss possible solutions like the explanation, neutralization or queering of care robots.

Thus, we contribute to the theoretical conceptualization of older people's vulnerabilities in increasingly digitalized care settings and draw conclusions for ethically sensitive technology development in eldercare.

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SELF-TRACKING AS A THREAT TO SOLIDARY HEALTHCARE? A POWER-CRITICAL APPROACH TOWARDS SOLIDARITY IN DIGITALIZED HEALTH CARE

Niklas Ellerich-Groppe¹

Presenter: Niklas Ellerich-Groppe

Parallel Session III, Room 3

Smart technologies enable an increasing personalization of health care services. This becomes salient in the phenomenon of self-tracking: Health- and fitness-tracking devices are used to control and optimize individual health behavior and to facilitate individually tailored medical prevention and care. While the insurance industry takes an interest in self-tracking data and promises better tariffs and bonus points for those with a healthy lifestyle, consumer protectors warn against personalized risks, discrimination and eroding solidarity. However, the concept of solidarity involved in these debates is often still less than clear, especially with regard to its normative implications and associated power-relations.

Against this backdrop, I propose and discuss a power-critical perspective on solidarity in digitalized health care. In an exploratory approach, I first map the relevant power-relations in conjunction with self-tracking data in the insurance industry.

As I will argue, these power-relations need critical reflection as they challenge common understandings of solidarity and thus the normative foundations of the welfare state. To this purpose, I provide an outline of a power-critical approach towards solidarity focusing especially on aspects of reciprocity and shared values as fundamental components of solidarity that are closely linked to power relations. Such an approach can help to re-conceptualize solidarity in the context of digitalized health care and thus provide a basis for critical analyses in smart bioethics.

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FEAR OF DEATH IN MEDICAL STUDENTS 1998-2019

**Montserrat Esquerda¹, Ana Isabel Parra², Anna M. Agustí²,
Josep Pifarre²**

Presenter: Montserrat Esquerda

Parallel Session I, Room 7

Medical students are close in their daily work with the world of suffering and death, living with pain and loss, without having received in general any regulated preparation to face it. This lack of training is associated with a sociocultural context that avoids speaking or approaching death, making it difficult for the medical student and the professionals themselves to develop the concept of death, adequate coping strategies, talking about complex decision-making at the end of life, acceptance of limitations or more generally to palliative medicine. This fear of death can hinder ethical decision-making and end-of-life conversations.

The aim of the study is to assess fear of death in a sample of medical students, from 1998 to 2019, the relationship between fear of death and age, gender, course, beliefs or experiences of death and assess the evolution of death during these 20 years.

Method

The study included 756 medical students, from the courses between 1998 and 2019, who were given Collet-Lester revised Scale of Fear of Death and a questionnaire of sociodemographic and biographical variables.

Results

The analysis of the variables surveyed indicates that medical students present an intermediate level of fear of death and the process of dying. Fear of death has increased in these decades; it also increases during medical courses.

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Conclusions

With the results obtained, medical schools should include a more oriented a specific approach in death and suffering that allows the medical student to obtain greater knowledge and be trained in accompanying death and talking about death.

THE EMBASSY OF GOOD SCIENCE: A COMMUNITY-BASED INITIATIVE TO STRENGTHEN RESEARCH INTEGRITY AND ETHICS

**Natalie Evans¹, Giulia Inguaggiato², Marc van Hoof²,
Bert Gordijn³, Kris Dierickx⁴, Ana Marusic⁵,
Guy Widdershoven²** on behalf of the EnTIRE consortium
Presenter: Natalie Evans

Parallel Session I, Room 5

The areas of Research Ethics and Research Integrity (RE+RI) are rapidly evolving. Guidelines, standards, and laws have been drafted in many countries, regions and institutions. However, the regulatory proliferation does not necessarily yield clear guidance for practice: researchers often lack up-to-date and easily accessible information and guidance on how to apply principles and norms. The same is true for RE+RI evaluation committees, who lack easy access to case studies.

The Embassy of Good Science is an online initiative to address these problems. The Semantic MediaWiki platform brings together, and makes smart connections between, relevant guidelines and regulations, cases and scenarios, and teaching materials. The platform provides practical information about how to apply norms and principles in every day practice and how to teach about them. For example, The Embassy contains cases and scenarios on researchers' day-to-day dilemmas, a discussion forum where researchers can share experiences, and easily adaptable teaching resources. Developed in consultation with stakeholders, the Embassy is managed by the European funded EnTIRE project. The initial content has been gathered via systematic reviews and is continually added to and updated by users. In the long-term, The Embassy will be community-owned and sustainable.

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The Embassy primarily supports researchers and RE+RI committee members. The platform also presents the opportunity to compare RE+RI principles, norms and practices worldwide, facilitating mutual learning and making the diversity of the RE+RI regulatory framework apparent. In this session, we will describe and demonstrate The Embassy's value for practice, education and policy.

RESULTS OF HIV AND STD TESTS: WHAT CONTRIBUTION OF INTERNET? WHAT ETHICAL ISSUES?

Nicolas Foureur¹

Presenter: Nicolas Foureur

Parallel Session III, Room 7

A specialized service for anonymous and free HIV and STD (sexual transmitted diseases) screening asked us, as a Clinical Ethics Centre, to reflect on the opportunity of making the results available to patients on the internet. Several options are possible: the provision might apply only to negative results or also to positive results, only for STD or also for HIV, to all patients or according to their own choice. In addition, if we consider that patients can manage alone the reception of their results, and to learn that they need to be treated, they might even choose to do the screening alone.

Based on the caregivers' appreciation of these issues (secretary, laboratory manager, nurses and physicians) and the work of the multidisciplinary clinical ethics group, this presentation will discuss:

- The ethical issues raised by these different possibilities. Do they contribute to a higher level of empowerment for patients? Do they constitute a benefit or a risk for either single patients or public health? What ethical considerations should ground the doctor-patient relationship in this context?
- The impact of the use of the internet or other technological means of communication in medicine. In the specific case of sexual health, technology can question the particular status with which information related to HIV testing is processed.

Perhaps these new procedures might help to fight the stigma related to HIV by treating the result of the screening process like that of other STD.

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A “SCHOOL OF CLINICAL ETHICS”: CLINICAL ETHICS EDUCATION FOR CLINICIANS AND PHILOSOPHY STUDENTS

Lucia Galvagni¹

Presenter: Lucia Galvagni

Parallel Session II, Room 5

The presentation intends to present and illustrate an experience of teaching clinical ethics realized with a group of clinicians and philosophy students and held at the Philosophy Department of the University of Trento, Italy (Spring 2013 and Spring 2015).

The class was intended to train clinicians and students to the main concepts of clinical ethics and to a specific methodology to approach clinical matters with ethical and philosophical tools. The class offered a space and time of listening, confronting, debating and learning.

The opportunity to dialogue and to reflect, starting from clinical cases presented by clinicians and to realize an ethical analysis of them, combining languages and competences, resulted extremely relevant for clinicians, for students involved and for the teachers themselves. It represented – as well – a first and previous step to start some action-research in specific clinical units, as the local Intensive Care Unit, the Transplantation Coordination Unit and the Mountain Medicine and Ethics Lab.

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HOW TO MEASURE GOAL CONCORDANT CARE IN ORDER TO EVALUATE ADVANCE CARE PLANNING WITH INTEGRITY: A LITERATURE REVIEW

Sophie Gloeckler¹, Manuel Trachsel²

Presenter: Sophie Gloeckler

Parallel Session I, Room 5

Advance care planning is an effort to consider and communicate one's values, goals, and preferences as they relate to future healthcare decisions to guide clinicians and loved ones when one is incapable of consenting, refusing, or requesting care. While generally accepted as valuable, advance care planning has proven challenging to evaluate. Goal concordant care is increasingly recognized as the target outcome, but there is no agreed-on methodology for assessment and some question if it can be meaningfully captured. It is ethically necessary to have a strong evidence base to guide practice.

The current study is a literature review designed to support best practice for measuring goal concordant care. A database search of Pubmed, Embase, PsycINFO, CINAHL, and Cochrane was conducted in September 2020; articles were included that measured whether advance care planning, defined broadly to consider advance directives, use of proxies, POLSTs, etc., led to goal concordant care. 132 included articles were reviewed according to aim, methodology, and integrity. Common approaches included medical record review 51% (n = 36); questionnaire (36%, n = 48), notably the Decision Conflict Scale (15% of questionnaires, n = 7); and interview (31%, n = 42), often with loved ones after death (40% of interviews, n = 17). Studies, especially those employing medical record review, did not always present enough detail to be reproducible, a concerning limitation.

Despite the many existing studies aiming to track whether advance care planning leads to goal concordant care, significant work remains to establish sound methodology to do so meaningfully.

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EMBRACING THE AUTONOMY OF CATHOLIC WOMEN – DISCUSSING THE HEALTHCARE AND ENVIRONMENTAL CONSEQUENCES OF THE CHURCH’S BAN ON CONTRACEPTION

Jan Greguš¹

Presenter: Jan Greguš

Parallel Session III, Room 2

The modern Catholic Church represents a body of 1.3 billion people who follow the Church’s teachings, given to them in the form of documents on different topics, including family issues. The latest, 2016 Apostolic Exhortation *Amoris Laetitia*, confirmed the previous documents on the topic, stating that periodical abstinence is the only contraceptive method possible for Catholic Christians. This means that 1.3 billion people are forbidden to use modern contraception. This significantly contributes to the spread of sexually transmitted infections (including AIDS/HIV pandemics) and the global epidemic of unintended pregnancies and their consequences (induced abortions, maternal and infant morbidity and mortality, etc.). These consequences are the most severe in sub-Saharan Africa and Latin America, where the Catholic Church prevails. Unintended pregnancies also greatly contribute to the rapid population growth currently being witnessed by humanity. As such, unintended pregnancies lead to severe environmental consequences (environmental degradation, resource depletion, species extinction, climate change, etc.). Unintended pregnancies are highly preventable if women are well-informed about family planning methods and if they are free to choose a contraceptive method based on their personal opinion, expectations, contraindications, and more. This merely underlies the important fact that voluntary family planning is fundamental to human dignity and critical for women’s health as well as the health of the planet.

For the aforementioned reasons, it is necessary to openly discuss the healthcare and environmental implications of the Church’s ban on modern contraception, and bring the Church’s representatives to acknowledgement of women’s autonomy to freely choose their preferable contraceptive method.

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INFORMED CONSENT FOR ORGAN TRANSPLANTATION IN OLDER ADULTS: ARE PATIENT DECISION AIDS THE SOLUTION FOR SUCCESSFUL IMPLEMENTATION OF SHARED DECISION-MAKING IN TRANSPLANT CLINICAL PRACTICE?

**Alessandra Agnese Grossi¹, Federico Nicoli², Jacopo Testa³,
Mario Picozzi⁴**

Presenter: Alessandra Agnese Grossi

Parallel Session III, Room 8

Informed consent (IC) in older adults (≥ 70 years of age) is often complex. This holds even truer in the setting of organ transplantation (OTx), requiring patients to be informed of the risks and benefits associated with multiple options: whether or not to pursue a transplant, to opt for a living – where appropriate – or deceased donor, to consider a variety of choices concerning the potential for poorer organ quality or increased risk of disease transmission and others. IC overlaps with shared decision-making (SDM) in the presence of high-risk procedures, with low levels of certainty, and when two or more treatment alternatives exist.

Patient decision aids (PDAs) (i.e. paper-based/electronic evidence-based tools) have been developed to complement and enhance SDM in clinical practice. Studies have proven PDAs to be an effective means to improve transplant knowledge, to foster patient participation, and to diminish decisional conflict

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across different settings in OTx. However, research is lacking on the effectiveness and appropriateness of these tools in older adults, which are increasingly entitled to receive OTx.

The objective of our work is 1) to present the challenges posed by the use of PDAs in this group of patients and 2) to identify gaps so as to inform the agenda for research on this emergent issue. Our findings suggest that future studies should aim to the development, implementation and evaluation of PDAs for the oldest, more vulnerable segments of this specific patient population.

SUPPORTING ETHICAL DECISION MAKING – A TOOL FOR ETHICAL REFLECTION ON CARE TECHNOLOGIES

Katrin Grüber¹, Elena Loevs kaya²

Presenter: Katrin Grüber

Parallel Session III, Room 5

The tool FreTiP (Fragen zur ethischen Reflexion von digitalen Technologien in der Pflegepraxis – questions on ethical reflection of digital technologies in nursing practice) was developed in 2020 by the Institute Mensch, Ethik und Wissenschaft (IMEW) as part of ELSI research in the PPZ-Berlin project. Our aim was to develop an instrument that stimulates and supports ethical reflection processes in the application of digital care innovation technologies in practice.

Ethical considerations are part of everyday (nursing) life, are closely interwoven with other aspects and are therefore difficult to recognise as such. The starting thesis of our work was that actors in care act on the basis of value concepts that they are more or less aware of. An ethics that is consciously integrated into everyday care takes into account all aspects that are relevant for an action or decision. In this respect, it is important to look at ethics in context and not to understand “ethics” as something isolated, coming from outside.

Based on this, the development of the instrument should not consist of “breaking down” ethical concepts and theories to practice, but of ethically locating, structuring and making applicable the experiences, questions and needs of the actors working in nursing practice. Thus, FreTiP is not only to be considered practice-oriented, but also to a certain extent practice-based.

The instrument was designed to be suitable for everyday care in clinics, care facilities and in the home context. FreTiP was developed as a low-threshold instrument that can be used flexibly and that takes into account the perspective of patients as well as carers.

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The development of the instrument was preceded by a triangulated study that included a literature review, interviews and (non-)participatory observations.

In the paper, experiences with the ethical reflection tool FreTiP will be presented.

CLAIMS OF MEDICAL MALPRACTICE IN THE AGE OF INFORMATION TECHNOLOGY

**Bianca Hanganu¹, Irina Smaranda Manoilescu²,
Beatrice Gabriela Ioan²**

Presenter: Bianca Hanganu

Parallel Session IV, Room 8

Introduction. Medical practice is almost constantly bending to new technologies, and in recent years, the health care system has been increasingly dominated by advances in information technology. Its use offers many advantages, but it also has its own risks.

Material and method. The authors conducted a literature review to see to what extent the accessibility and effective use of information technology, i.e. electronic health records (EHR) influence risk of malpractice.

Results. The literature refers both to how EHR use can prevent malpractice claims, and how it can increase their number. Thus, EHR can prevent medical errors and associated complaints by: instant access to complete patient information (including laboratory and imaging results); improving communication between medical team members; reducing drug errors (e.g. drug interactions, allergic reactions); prompt request for further investigations. However, the misuse of EHR can create new problems: inadequate training with errors from implementation and accommodation; automatic or unexpected deletion of the recommended medication; the temptation to use the information obtained previously and the circumvention of the stage of obtaining a new medical history or the temptation to copy and paste the information from the previous consultations to the current consultation - which will lead to the perpetuation of errors and omissions from the previous consultations; increased risk of privacy and confidentiality breach. Likewise, certain facilities that these systems allow may be ambivalent, and may both reduce or increase the risk of

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complaints, depending on how they are used: communication between doctor and patient through messages, including updating prescriptions and reporting symptoms that require prompt evaluation but at the same time, delay in response may dissatisfy the patient.

Conclusions. The implementation of EHR brings many advantages, both for the patient and for the medical staff in terms of accessing information, facilitating communication and carrying out treatment plans, but the medical staff must be constantly aware of the risks involved, especially related to their proper use.

UTILIZING APPLIED DRAMA IN CLINICAL ETHICS EDUCATION

Kenji Hattori¹

Presenter: Kenji Hattori

Parallel Session III, Room 6

We examine the significance and necessity of introducing applied drama into clinical ethics education to build ethics competency. Case-based clinical ethics, distant from abstract theory-based discursive ethics, pays close attention to emotions of persons involved in a given case, and of participants in deliberation. Some authors have sensibly emphasized this point. For example, CURA, a reflective method puts forward the crucial step to become aware of own emotions and physical reactions to each difficult situation. These suggest that we should not stay just in rational reasoning to resolve moral problems in clinical settings. Such a stream seems to lead us to the next stage of clinical ethics education.

Applied drama is an umbrella term for the various ways to use theatrical elements, outside of theaters, in educational settings. The basic conception is playing. It includes two meanings: gaming and acting. Generally, we stop playing when we grow up. Applied drama encourages us to play again. Playing promotes communications in verbal and physical. In acting like an acting person, we are to put ourselves in another person's standpoint. Through acting a role, we may live her life and feel vividly his emotion but by imagination. Thus, applied drama has great potentiality to change the mode of discussion – or deliberation-based clinical ethics. As applied drama comprises various ways such as improvisation, forum theatre, and so on.

We will explore their features and application in actual teaching settings.

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ETHICAL VALUES REASSESSED: RETHINKING THE COVID19 PANDEMIC FIRST TRIAGE GUIDELINES

Sabine Hauser¹, Rouven Porz², Maria Aluaș³

Presenter: Sabine Hauser

Parallel Session I, Room 1

In March 2020, many countries in commissions and medical societies moved very quickly to draft fair and transparent triage guidelines; this in order to plan ahead for possible resource bottlenecks in the treatment of COVID-19 patients in intensive care units. There are a lot of consciously chosen (but also less reflected) ethical values in these guidelines. Our presentation compares the values of eight of such guidelines, but first shows how to read such values in the first place. Many health professionals are hardly aware of the explicit presentation of ethical-philosophical values.

From a methodological point of view, this presentation is based on a hermeneutic-ethical approach. The guidelines are interpreted, an interpretation aid is developed, and the values of the guidelines are reconsidered in comparison.

On a meta-level, we could identify different types of values, besides medical and ethical values, the guidelines were also filled with procedural, structural and legal-political values. On a content level, the unreflective handling of the value of autonomy, which often competes with the value of public health, is particularly evident. This competition is little reflected. Another point of divergence between the guidelines is the degree of precision or the difference between long-term and short-term medical prognosis.

We believe that with our analysis we can contribute to making value discussions in health care more open and explicit. We would like to present these conclusions for discussion at this year's EACME conference in Cluj.

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ADDRESSING THE EVIDENCE GAP IN MEDICATION FOR PREGNANT WOMEN: THE NEED FOR MORE SOLIDARITY?

Marieke Hollestelle¹, Rieke van der Graaf², Miriam Sturkenboom², Hans van Delden²

Presenter: Marieke Hollestelle

Parallel Session III, Room 3

Although the inclusion of pregnant women in clinical research has been widely promoted over the last decade, there is still a lack of evidence-based knowledge concerning risk and efficacy of medications used for obstetric and non-obstetric illnesses. It has been argued that solidarity is of key importance in changing the status quo for the group of rare disease patients, for whom, just like pregnant women, a poor evidence-base exists regarding treatments. Therefore, we explore the potential role of solidarity in changing the status quo in the field of pregnant women.

By way of an in-depth analysis of the concept of solidarity developed by Barbara Prainsack and Alena Buyx, we assess the role of solidarity in the group of rare disease patients and apply the conditions for solidarity to the group of pregnant women. From this analysis, we derive three lessons for the group of pregnant women: 1) being able to self-organize can have a significant effect on the ability to demand change, 2) organizing and action can be triggered by commonalities, such as shared experiences 3) enabling change involves enacted commitments to accept a cost to assist others with whom one recognizes a similarity in a relevant respect. In this presentation, we argue that an active involvement of pregnant women described as an act of solidarity should be stimulated.

With that, engagement and solidarity from other stakeholders involved are necessary to raise awareness about the shared experiences of pregnant women and to realize the infrastructure for active involvement.

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SHARING WHILST CARING: SOLIDARITY AND PUBLIC TRUST IN A DATA-DRIVEN HEALTHCARE SYSTEM

Ruth Horn¹, Angeliki Kerasidou²

Presenter. Ruth Horn

Parallel Session II, Room 4

In the UK, the solidaristic character of the NHS makes it one of the most trusted public institutions. In recent years, the introduction of data-driven technologies in healthcare has opened up the space for collaborations with private digital companies seeking access to patient data. However, these collaborations appear to challenge the public's trust in the healthcare system.

In this paper we explore how the opening of the healthcare sector to private digital companies challenges the existing social contract and the NHS's solidaristic character, and impacts on public trust. We start by critically discussing different examples of partnerships between the NHS and private companies that collect and use data. We then analyse the relationship between trust and solidarity, and investigate how this relationship changes in the context of digital companies entering the healthcare system. Finally, we show ways for the NHS to maintain public trust by putting in place a solidarity grounded partnership model with companies seeking to access patient data. Such a model would need to serve collective interests through, for example, securing preferential access to goods and services, providing health benefits, and monitoring data access.

A solidarity grounded partnership model will help establish a social contract or licence that responds to the public's expectations and to principles of a solidaristic healthcare system.

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MANAGEMENT OF MEDICAL DATA IN EMERGING THREATS

Sorin Hostiuc¹

Presenter: Sorin Hostiuc

Parallel Session III, Room 7

Emerging viral or bacterial threats pose significant medical and ethical issues, caused not only by the management of the disease, but also by the uncontrolled dissemination of information, both true and fake. Even the most correct and impartially presented piece of information can be understood by the patients or by the public at large in ways that are opposite to those intended by the communicators. This, associated with the increased prevalence of fake news, may cause havoc and decrease the efficacy of the needed preventive measures that have to be taken to tackle the actual medical problem.

Within the context of the coronavirus outbreak, this has been coined as “infodemic”, increasing the difficulty of finding an optimal solution to the actual problem. Medical data about an emerging medical threat is disseminated through mass – and social media, especially by public authorities and physicians. The latter have specific duties, appertaining to their professional codes of morals, toward minimizing the harms generated by diseases, both at a personal and at a populational level. In infodemics, the management of the information they present to the public is extremely important, as each wording can be improperly interpreted and cause opposite effects.

In this paper, we will discuss whether and which healthcare professionals should be involved in disseminating information about emerging healthcare threats, and which moral duties should prevail in these instances.

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PROMOTING RESPONSIBLE RESEARCH PRACTICES BY TRAINING RESEARCHERS' VIRTUES

**Giulia Inguaggiato¹, Nathalie Evans², Margreet Stolper³,
Bert Molewijk³, Guy Widdershoven³**

Presenter: Nathalie Evans

Parallel Session I, Room 5

Promoting research integrity is crucial to achieve high quality and relevant results, and preserve public trust in science. In recent years, many codes of conducts, guidelines and regulations on national and international level, such as the European Code of Conduct for Research Integrity, have been issued to tackle this issue. However, these documents are often perceived as an externally imposed set of rules that researchers need to comply with in order to tick the box of integrity and get their research done.

These research integrity efforts are important, but are they enough? We argue that in order to foster 'good' science, educating 'good' researchers is crucial. To respond to these issues, the VIRT2UE project has created an open source online training for researchers and educators that supports the internalization of the practices and principles of good science by building upon a virtue-based approach. Core elements of this approach are reflections on the intrinsic motivation of researchers and the cultivation of those moral characters which support the practices and principles of good science.

The VIRT2UE training consists of a toolbox with training materials which can be used both online and offline, easy to use and adaptable to context. Starting from the assumption that virtues are learned through experience and by example, we will show what role trainers and educators can play in promoting a virtue-based approach to research integrity and what this implies for their own education and professionalization as trainers.

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ETHICAL ASPECTS OF USING VIRTUAL REALITY IN PSYCHIATRY

**Oana Maria Isailă¹, Sorin Hostiuc², Filip Curcă²,
George Cristian Curcă²**

Presenter: Oana Maria Isailă

Parallel Session II, Room 7

Virtual reality (VR), initially a form of entertainment has begun to find its way in healthcare practice. One of its main areas of interest is the treatment of psychiatric disorders. When using VR, the basic ethical principles underlying the physician-patient relationship should be respected, but they should be customized by the presence of an additional layer of complexity generated by the interposition of the virtual world.

The physician-patient relationship is often multidirectional, often including a larger team of healthcare professionals, family members or acquaintances, working conjointly to optimize the medical care. Each time other participants are involved within this relationship, the complexity of the ethical issues tends to increase. For example, if the patient has decreased insight, it is possible that other persons must make some medical decisions – resulting a prioritization of beneficence compared to autonomy. Also, we must take into account the fact that many psychiatric symptoms can be seen as a form of “virtual reality” by the patient. The healthcare provider must take additional safety measures to minimize the harms made by VR techniques in psychiatric patients, by using methods that are individually tailored.

The main aim of this paper is to debate the ethical aspects surrounding the applicability of virtual reality in treating psychiatric patients, with an emphasis on the elements that were mentioned earlier.

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ETHICAL ASPECTS IN ANIMAL ASSISTED THERAPY IN PSYCHIATRY

Oana-Maria Isailă¹, Sorin Hostiuc², George-Cristian Curcă²

Presenter: Oana Maria Isailă

Parallel Session IV, Room 3

Animal-assisted therapy is a complementary therapy in which an animal that meets certain well-defined criteria is an integral part of the therapeutic process. It has proven its positive contribution in treating disorders such as ADHD, autism spectrum disorders, depression, anxiety, panic attacks, PTSD, phobias, suicidal ideation. Human-animal interaction lowers stress, anxiety and increases quality of life.

The therapy animal, in order to have the expected motivating role, must have a balanced personality and want to interact with people. In this sense, it goes through training programs based on obedience and desensitization to certain stimuli. This peculiar context raises ethical issues for the patient and the animal co-therapist, which requires setting boundaries. Although the legal framework sets out the elements on animal welfare, ethical issues that arise for animals are: the animal species that may be involved, limiting their freedom, endangering their welfare, the risk of exploitation (which can lead to their fatigue and burn-out), the type of interaction -which must be voluntary, bidirectional.

Regarding the patient, in addition to the aspects related to beneficence and nonmaleficence, there are issues in obtaining an adequate informed consent (targeting possible allergies, some religious / cultural beliefs incompatible with this type of therapy). Thus, animal-assisted therapy must take into account the benefits of both parties involved, without instrumentalizing the animals.

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DOES INSTITUTIONALISING REASONABLE ACCOMMODATION INCREASE CONSCIENTIOUS OBJECTIONS OF MEDICAL PROFESSIONALS?

Ryoko Ishikawa¹

Presenter: Ryoko Ishikawa

Parallel Session IV, Room 1

In January 2020, the Council of Europe has rejected a resolution that recommends reasonable accommodation of employee's religious practices in the workplace. The concept of reasonable accommodation emerged in the United States and in Canada to allow some flexibility in the application of laws to achieve substantial equality for all, as uniform application of seemingly neutral laws can cause disadvantages to ethnic or religious minorities, and people with disability. However, reasonable accommodation of religious practices in the workplace such as hospitals is often criticised in two ways; first, it makes it easier for the doctors to register a conscientious objection against providing abortion or reproductive treatment and thus harms women's reproductive rights. Second, in the same manner, medical professionals may use reasonable accommodation as an excuse to refrain from providing certain medical care to sexual minorities.

The purpose of this paper is to indicate that such secularist criticisms of reasonable accommodation are implausible. To show this, this paper first reviews the idea of reasonable accommodation in North America and Europe. Then, the reasonable accommodation debate occurred in Québec, Canada and the report by Bouchard-Taylor Commission (2007-2008) are examined in light of theories of deliberative democracy to illustrate the asymmetry of power between the majority and the minority groups in the negotiation process. Lastly, this paper argues that reasonable accommodation as a means to negotiate the demands for accommodation of religious practices is limited. Thus it is unlikely to undermine the fundamental liberal values of the majority.

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ATTITUDES AND OPINIONS OF MEDICAL STUDENTS AND HEALTH CARE PROFESSIONALS ABOUT THE COVID-19 VACCINE (A QUANTITATIVE STUDY FROM A MEDICAL SCHOOL AND ITS AFFILIATED HOSPITALS)

**Yesim Isil Ulman¹, Arshiya Abbaszadeh², Beril Ay²,
Diyar Dogrucam², Mirkan Dikec², Shahad Al-Amoudi²,
Yaren Nur Demir², Sahin Senay³**

Presenter: Yesim Isil Ulman

Parallel Session 1, Room 6

Objectives: Vaccination is one of the most effective scientific inventions to prevent infectious diseases worldwide. Despite the evidence on the efficacy of vaccinations, vaccine refusal still poses a threat for human health. This study aims, firstly, to detect the underlying reasons of vaccine hesitancy concerning the COVID-19 among medical students and healthcare professionals; and, secondly, to compare the results between the two groups.

Methods: This is an online, ongoing cross-sectional quantitative study based on a scale validated in the socio-cultural context in Turkey. The sample consists of students of medicine at six years of education including preparatory class at a foundation university in Istanbul, as well as the healthcare professionals at the affiliated hospitals of the same university. Data will mainly be collected through the Scale of Vaccine Hesitancy (1) annexed with demographic and open-ended questions detecting opinions about vaccination. T-test and chi-square tests will be used for the analysis of scale scores and demographic questions respectively. The open-ended questions will provide deeper findings on the issue.

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Discussion and Conclusion: While COVID-19 pandemic remains a global challenge, vaccine roll-out seems to be the best response to combat the disease. However, reluctance in acceptance of vaccines among diverse populations creates a risk for herd immunity. Comparatively investigating the motives of vaccine hesitancy among health-related populations may help proposing social, ethical guidance for medical education and health policies.

Source: Kilincarslan, M. et al (2020). Development of Valid and Reliable Scale of Vaccine Hesitancy in Turkish Language. *Konuralp Tıp Dergisi*, 12(3), 420-429

PHYSICIAN APPROACHES TO ADDRESSING CONFLICT ARISING IN END-OF-LIFE DECISION-MAKING IN THE ADULT INTENSIVE CARE UNIT: A SYSTEMATIC REVIEW

Harleen Johal¹

Presenter: Harleen Johal

Parallel Session I, Room 3

Background: Conflict is unfortunately well-documented in the adult intensive care unit (AICU). In the context of end-of-life (EOL) decision-making (i.e. the withdrawal or withholding of life-sustaining treatment), conflict commonly occurs when a consensus cannot be reached between the healthcare team and the patient's family on the "best interests" of the critically ill, incapacitated patient, as per England's Mental Capacity Act 2005. Whilst existing literature has identified potential routes for conflict resolution, it is less clear how these approaches are perceived and utilised by stakeholders in the EOL decision-making process.

Aim: We aim to explore this by systematically reviewing and synthesising the published evidence, which addresses the following research question: what does existing qualitative research reveal about physician approaches to addressing conflict arising in EOL decisions in the AICU?

Methods: Peer-reviewed qualitative studies (retrieved from MEDLINE, Project Muse, EMBASE, Web of Science, PsycINFO, CINAHL and LILACS) examining conflict and dispute resolution in the context of EOL decisions in the AICU setting will be included. Two reviewers will independently screen for eligibility and extract data from either all or 10% of the included studies, with a third reviewer independently screening studies of uncertain eligibility. The 'thematic synthesis' approach will be utilised to analyse the resulting data (Thomas & Harden, 2008).

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HARLEEN JOHAL

The systematic review is currently underway, laying the foundations for a larger empirical study, undertaken for a PhD, funded by the Wellcome Trust BABEL (Balancing Best Interests in Healthcare, Ethics, and Law) Collaborative Award. The results will be presented at the conference.

MEDICALISATION AND THE TREATMENT-ENHANCEMENT DISTINCTION IN THE ETHICAL DEBATE ON GENE EDITING

Tess Johnson¹

Presenter: Tess Johnson

Parallel Session I, Room 7

Since the advent of CRISPR/Cas9 gene editing technology, much bioethical effort has been devoted to prescribing the appropriate potential uses of gene editing in humans. Frequently in the literature, a normative distinction is drawn between “treatment” and “enhancement”. That is, gene editing may be morally acceptable or even morally required if used to cure a disease or genetic condition. For enhancement, however, it is morally unacceptable, having too weak a justification for the risks involved.

In the context of this new technology, we all thus become vulnerable to a bias: medicalisation. There are clear non-medical benefits, as I show here, of using gene editing not for treatment, but for enhancement. Many individuals and governments will wish to pursue these benefits, but if we are ethically constrained by the current perceived force of the treatment-enhancement distinction, we may be prevented from legitimately doing so. We are faced with two options: firstly, to reject the distinction presented by many ethicists, and pursue gene editing for both treatment and enhancement purposes; secondly, to expand medical definitions and the scope of health care, to include the sort of benefits that we might wish were included under “treatment”.

The first option, I argue, is to be preferred, but at least currently, faces much public resistance. Instead, we risk the second option becoming the norm, with the medicalisation of scores of non-medical characteristics drawing resources, causing anxiety, and burdening health care systems, because of stubborn adherence to an arbitrary distinction in the gene editing debate.

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ATTITUDES TOWARDS ASSISTED SUICIDE AMONG HOSPITAL WORKERS: RESULTS OF A LARGE MULTIPROFESSIONAL SURVEY IN FRENCH-SPEAKING SWITZERLAND

Ralf J. Jox¹

Presenter: Ralf J. Jox

Parallel Session I, Room 2

Background: Worldwide, assisted dying is currently on the rise. For health care professionals (HCP), this raises questions regarding roles and responsibilities. Switzerland is a social laboratory for a non-medicalized form of suicide assistance (SA).

Aims: To describe experiences and attitudes of Swiss HCP toward SA in the hospital setting and to identify associated factors.

Methods: An online questionnaire survey targeted all HCP involved in patient care at two tertiary hospitals in French-speaking Switzerland. The primary outcome was a favorable attitude toward SA. Associated factors were assessed using logistic regression.

Results: A total of 5127 professionals responded (37.1%). The sample was representative of the hospitals, with 74% being female, 52% nurses, 23% physicians and 25% other professions. 69% supported the view that each HCP should have the choice to participate or not in SA. The majority favored access to SA in case of severe somatic illnesses, irrespective of prognosis, but less for patients with mental disorders or healthy seniors. 60% of all HCP were generally ready to be involved in SA, but only 30% of physicians would prescribe a lethal substance. 58% of HCP would consider assisted suicide for themselves in certain circumstances. Independent factors associated with a favorable attitude toward SA were: younger age, graduation in Switzerland, non-physician profession. Working in palliative care or being protestant was associated with a less favorable attitude.

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Conclusion: The diverse attitudes of HCP suggest that the Swiss model of SA may have to be reconsidered, including the question about the participation of hospital workers.

CONSIDERING THE ROLE AND NATURE OF EMPATHY, COMPASSION AND TRUST IN THE ERA OF AI IN HEALTHCARE

Angeliki Kerasidou¹

Presenter: Angeliki Kerasidou

Parallel Session III, Room 3

Empathy, compassion and trust are fundamental values of a patient-centred, relational model of care. In recent years, quest for greater efficiency, including economic efficiency, has often resulted in the side-lining of these values, making their practice difficult.

Artificial Intelligence (AI) is increasingly entering healthcare promising greater efficiency and more free time for healthcare professionals to focus on the humanist side of care, including fostering trust relationships and engaging with patients with empathy and compassion.

This paper problematises the vision of efficient, empathetic and trustworthy care put forward by the AI proponents. It suggests that AI has the potential to fundamental alter the way in which empathy compassion and trust are currently considered and practiced. Moving forward, it is important to re-evaluate whether and how these values could be incorporated and exercised in an era of AI healthcare, but most importantly to re-examine what kind of healthcare society ought to promote.

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ETHICAL QUARANTINE IN THE GLOBALIZED AGE

Satoshi Kodama¹, Miho Tanaka²

Presenter: Satoshi Kodama

Parallel Session I, Room 1

The outbreak of a new coronavirus disease (later named COVID-19) was first reported in China, and it then spread to other countries, including Asia and Europe. In a bid to contain the further spread of the disease, several government resorted to large-scale quarantine, notably in the city of Wuhan in China (more than 11 million people), a cruise ship of Yokohama in Japan (around 3,600 people), and several towns in Northern Italy (about 50,000 people altogether). While the WHO praised China for its attempt to stop the spread of the virus by quarantine, there were also many criticisms of such quarantine as it involved putting severe limitations on the liberties of individuals inside the cordon.

In this presentation, we would like to enquire which conditions need to be met for the quarantine to be ethically justified. First, we will briefly discuss the definition of quarantine and similar terms, such as isolation and social distancing. Second, we will tease out the criteria for ethical quarantine by critically examining the literature on the ethics of quarantine, most of which are based on the experience of SARS and Ebola. Third and the last, we will put these criteria to test by applying them to the examples mentioned above of quarantine in China, Japan, and Italy.

This kind of exercise is necessary for us to prepare for the next emergence of new infectious diseases.

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LEARNING PRACTICAL WISDOM FROM MORAL CASE DELIBERATION THROUGH MORISPRUDENCE

Jos Kole¹

Presenter: Jos Kole

Parallel Session IV, Room 7

Moral case deliberation is regularly used as a teaching method at our medical school. Besides we facilitate moral case deliberation on the ward in our hospital. In both instances, our assumption is that practicing moral case deliberation will assist our (future) healthcare professionals to cultivate the virtue of practical wisdom. But, is this assumption, right? The answer to this question requires both empirical research and conceptual analysis.

This paper focuses on the latter. The claim defended is that we can elucidate the relation between moral case deliberation and practical wisdom through an analysis of so called morisprudence. We start with discussing two divergent but related interpretations of morisprudence: one introduced by Toulmin and Jonsen, related to casuistry, and one related to a Dutch interpretation with a strong relation to moral case deliberation. The combination of the both interpretations shed new light on the conceptual connections between cultivating prudence (practical wisdom) and moral case deliberation, but it also provides new insights into the individual and collective dimensions of practical wisdom, of character formation within organizational contexts.

Finally, it may have consequences for how moral case deliberation should actually be employed to teach practical wisdom.

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DEVELOPING ORGANISATIONAL DIVERSITY STATEMENTS THROUGH DIALOGICAL CLINICAL ETHICS SUPPORT: THE ROLE OF THE CLINICAL ETHICIST

Charlotte Kröger¹, Suzanne Metselaar², Bert Molewijk²

Presenter: Charlotte Kröger

Parallel Session III, Room 5

In increasingly pluralist societies, stakeholders in healthcare do not always share a common moral perspective on health, wellbeing or good care. Growing cultural, religious, and sexual diversity among both patients and healthcare professionals (HCPs) require healthcare organizations to address these differences and to engage in inclusive and equitable practices. Addressing diversity, however, comes with inherent moral challenges. For example, regarding how to deal with healthcare disparities between minoritized and majoritized patients. Additionally, increasing diversity in the workforce means that HCPs moral perspectives on 'good care' are diversifying.

Developing diversity statements is an important strategy for healthcare organizations to define their normative ideas, values, and approaches to both care and diversity. To tackle concerns of exclusion and power differences, and to ensure that these statements reflect a common ground among HCPs, healthcare organizations ought to develop diversity statements in an inclusive and participatory way. Clinical ethics support (CES) services and interventions such as Socratic Dialogues can be employed to help healthcare organizations to do so.

In this presentation, we (1) argue for taking a participatory approach when supporting *healthcare* organisations in developing diversity statements, (2) report both on the content and the process of developing a diversity statement through

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CES and Socratic Dialogues, and (3) maintain that CES that supports processes of joint reflection and learning among stakeholders can be used in such an approach.

We will use a case example from practice to illustrate our point.

We conclude with several recommendations regarding a participatory CES approach for developing diversity statements.

THE 'DIVERSITY-COMPASS': DEVELOPING AN INSTRUMENT FOR HEALTH CARE PROFESSIONALS TO DEAL WITH MORAL ISSUES CONCERNING CULTURAL, RELIGIOUS AND SEXUAL DIVERSITY IN LONG-TERM CARE ORGANIZATIONS

Charlotte Kröger¹, Suzanne Metselaar²
Presenter: Charlotte Kröger

Parallel Session II, Room 6

Culture, religion, gender identity and sexual orientation play an important role in patients' and professionals' care preferences and communication. Population diversity leads to differing moral perspectives regarding health, wellbeing and care practices. This can generate value conflicts between patients and professionals concerning what good care is. Accordingly, increasing societal pluralism creates novel challenges for professionals regarding how they ought to deliver equitable and diversity-responsive care to minority populations. To support professionals in dealing with moral issues related to cultural, religious and sexual diversity in long-term-care organizations, we developed an ethics support instrument called the Diversity-Compass. The Diversity-Compass is a low-threshold instrument designed to help professionals in addressing and dealing with situations in which moral conflicts pertaining to diversity occur.

We employed a participatory design and conducted seven focus groups (n=55), five expert interviews (n=5) and facilitated four meetings with a working group of various care professionals (n=18) who developed and tested preliminary versions of the instrument through iterative co-creation. Resulting from this process the Diversity-Compass emerged. Next to offering a question-based, reflection-invoking conversation method, the instrument includes seven specific tips to support professionals when engaging in conversations about diversity-related moral issues with patients or other professionals.

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Our study is an example of how bioethicists can provide clinical ethics support by using a participatory design and co-creatively developing an instrument to aid professionals in dealing with moral issues related to cultural, religious and sexual diversity in long-term care. The Diversity-Compass can be used by organizations and professionals to promote good, diversity-responsive care.

BIOCOLONIALISM AND INFORMED CONSENT. THE HAVASUPAI CASE

Barbara Krzyżewska¹

Presenter: Barbara Krzyżewska

Parallel Session IV, Room 8

A core value in research ethics is respect for individual's autonomy. For the researcher the way to respect this value is to guarantee informed consent to the participants. Nowadays more and more research is conducted on biological material of human origin rather than on humans. But apart from that, informed consent must be guaranteed.

The case I would like to present and comment is the Havasupai case. Havasupai are an indigenous tribe lived in Grand Canyon. Due to the high percentage of diabetes type 2 among members of the tribe, the tribe decided to take part in the research conducted by the researchers from Arizona State University. In this case were a few vague aspects, which I will present during the speech, but one thing I especially notice. In the scientific community there was a great interest in obtaining Havasupai blood samples. It was caused by the fact that Havasupai are an indigenous people and they do not start a family with people out of them tribe. Because of that their DNA is scientifically more interesting than the DNA of people out of the tribe.

That approach is called biocolonialism. In the past indigenous people were used because of the sources that they had on their lands. Now their DNA is a scientifically valuable source of information. Moreover, in literature it is said that researchers – the new (bio)colonizers – are conducting a “helicopter research”. They came up, took what they want and disappear.

In my speech I would like to analyze problems raised in Havasupai case and present what the biocolonialism means in and for research.

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FROM GENE-EDITED BABY TO CYBORG SOLDIER: ON THE LIMITS TO NEW BIOTECHNOLOGY BY THE EUGENICS MOVEMENT

Chang-Yun Ku¹

Presenter: Chang-Yun Ku

Parallel Session III, Room 1

Biotechnology for Health and Human Performance (BHPC) of the U.S. DOD recently released a research report titled “Cyborg Soldier 2050: Human/Machine Fusion and the Impact for the Future of the DOD”. In this report, Emanuel et al. predicted that ocular and auditory enhancements, muscular control through bodysuit, and neural enhancement of human brain will be feasible before 2050. And not so long ago, the world’s first Gene-edited twins LuLu and NaNa were made by a Chinese Scientist, who was sentenced and fined by the Chinese Government in December 2019, claims that these babies are now immune to the HIV virus. While the biotechnological breakthroughs show the potentials that humans can have different lives than we have now, it’s also worrisome for those unforeseen disadvantages of bio-inventions will cost human too much and too soon, before we have the abilities to stop it.

Along with the developments of biotechnology, it’s not surprised that new bio-inventions will emerge and go beyond our imagination. But, the “artificial selection” character of these bio-inventions also reminds us of the Eugenics Movement which happened only a century ago. In this article, I’ll discuss these two bio-inventions by reviewing the Eugenics Movement. First, I’ll brief the cases of Gene-edited Baby and the CRISPR technology as well. Second, I’ll introduce the Cyborg Soldier and BHPC’s report. Third, I’ll talk about the Eugenic Movement and its consequences. Fourth, I’ll analyze these two bio-inventions from the historical perspectives of the Eugenic Movement. Finally, I will summarize and conclude this article.

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CO-CREATION: A NOVEL APPROACH TO DEVELOPING GUIDELINES FOR RESEARCH INTEGRITY POLICY – LESSONS LEARNED FROM THE SOPS4RI PROJECT

Krishma Labib¹, Joeri Tjiddink²

Presenter: Krishma Labib

Parallel Session II, Room 5

Co-creation is a qualitative research methodology that engages stakeholders in playful activities to produce user-centered outputs. Through an interactive and open approach, co-creation explores stakeholders' latent values, generates innovative ideas, and captures minority views, allowing for in-depth understanding of how stakeholders are affected by various factors. Therefore, co-creation is a promising methodology for developing guidelines on research integrity (RI), although there is no literature available about co-creation in this context.

In our presentation, we share experiences of using co-creation to design institutional guidelines on RI together with research managers, funders and researchers across Europe. We conducted 24 co-creation workshops on topics ranging from RI education, to creating a responsible research environment, resulting in concrete guidelines that research institutions and funders can implement to foster RI. Our experience has provided us with valuable insights on using co-creation for RI guideline development. While motivating research stakeholders – often serious and analytically oriented people – to engage in creative exercises can be a challenge, particularly in the online setting, it is possible to achieve when 'play' and 'work' are carefully balanced.

Additionally, to ensure the concreteness of guidelines while accounting for differences among institutions and countries, best practice examples can be used to show different approaches to implementing more general guidance.

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We have also learned that it is valuable to explore stakeholders' preferences regarding the guideline format, since implementability is not only influenced by the content.

These insights provide practical considerations that other researchers can use when co-creating RI guidelines.

MORAL CHALLENGES OF ETHICS SUPPORT STAFF. DEVELOPING A MORAL COMPASS FOR FACILITATORS OF MORAL CASE DELIBERATION

Wieke Ligtenberg¹, Margreet Stolper², Bert Molewijk²

Presenter: Wieke Ligtenberg

Parallel Session II, Room 2

Ethics support staff often help others to deal with moral challenges. However, they themselves can also experience moral challenges when practicing ethics support. Facilitators of Moral Case Deliberation (MCD) sometimes for example experience ethical questions when it comes to (breaking) confidentiality. Facilitators might find themselves compelled to intervene or act upon things they hear or see whilst facilitating a MCD. For example, a MCD facilitator finds out that a participant does something illegal. Or, what to do if a MCD facilitator is asked to inform the Inspectorate about details of a MCD? When is a facilitator allowed or obligated to break confidentiality and share information with others? How to make such a decision? And, if allowed to break confidentiality, how to do this in a morally sound way?

Currently there are no moral guidelines on how to act upon these questions. We conducted empirical research that explores moral challenges of MCD facilitators related to confidentiality and develops a moral compass which provides directions to approach these challenges. Data collection consists of three complementary methods:

- * analyses of 3 a 4 audiotaped and transcribed MCD sessions about how and when to break confidentiality;
- * in-depth interviews about the topic;
- * focus group to validate the findings and co-create a moral compass.

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In our presentation, we will reflect upon both the theoretical and normative considerations concerning confidentiality in ethics support and the empirical results of this study. Furthermore, we will present a preliminary version of a moral compass in order to strengthen the moral competency of MCD facilitators.

SHIFTING RESPONSIBILITIES IN MEDICINE 4.0 – A PROJECT REPORT

Georg Lindinger¹, Bettina Schmietow²

Presenter: Georg Lindinger

Parallel Session II, Room 8

In this contribution, we anticipate the results of the research project “Medicine 4.0 – the ethical basis of digitalization in healthcare” funded by the German Ministry of Health, which investigated the ethically relevant effects of digitalized medicine using mobile health (mhealth) and telemedicine as prime examples, with the final aim of deriving policy-relevant overarching recommendations. In an iterative interdisciplinary approach, we linked social science research with analytic research on the ethically relevant effects of these technologies, including on the doctor-patient relationship, the relationship between responsibility and solidarity in healthcare and on the autonomy of the individual.

In both the ethical and social science research, a key focus concerned the identification and analysis of an apparent diversity of stakeholder values and perspectives. In mobile or mhealth, which we concentrate on for this presentation, technology developers, insurances, physicians and public health professionals as well as ‘patient-consumers’ need to be looked at and involved. Their outlook in turn may converge, but also be in tension or collide, e.g. regarding conditions for data access and use, liability in case of malfunction or misuse and the overall question of responsibilities in a context of shifting roles and role anticipations.

The research combines ethical insight and expert stakeholder perspectives on the most pressing issues in this fast-moving field. Further, traditional issues such as informed consent, confidentiality and the role of individual autonomy, are in part redefined with the emerging role of automated or algorithmic decision-making.

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PRECLINICAL LECTURES IN MEDICAL FORMATION: PROFESSIONALISM, ETHICS AND RESPONSIBILITY

Cristian Cezar Login¹, Simona Clichici²

Presenter: Cristian Cezar Login

Parallel Session I, Room 6

Future doctors are the result of the present-day medical education and they bear the professional and attitudinal imprint of their mentors and instructors. The academic interaction between students and professors represents a key element in the scientific and professional training of future health care providers. Preclinical disciplines represent the foundation of the medical training system, on which the student will develop and integrate clinical skills. Therefore, preclinical topics have to offer accurate and updated information, working paradigms, and approaches to the development of professional values and ethical attitudes.

Taking as starting point the teaching experience of the authors, we focused on the analysis of the interaction between three key concepts – professionalism, ethics and responsibility – concerning both the instructor and the student. These interrelated concepts will be approached from the viewpoint of all participants, instructors and students, in the contemporary context of the enormous volume of ever-changing scientific information and of the easy access to it. In order to select accurate data needed today and equally oriented towards future, information should always be filtered.

The instructor is responsible not only to provide students with scientific data but also to stimulate and to develop flexibility, openness and critical thinking, while respecting ethical values. Through the offered scientific content, approaches, professional values and ethical attitudes, instructors transmit to the students a model of integrity in profession, ethics and responsibility, which will have consequences on the way they will choose to practice health care and medical research professions.

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ETHICS, DATA AND INFORMATION IN GENOME SEQUENCING IN NEWBORNS

**David Lorenzo¹, Montserrat Esquerda², Margarita Bofarull²,
Francesc Palau³, Jose Javier Ordoñez², Victoria Cusi²,
Francisco J. Cambra³, Marc Illa², Joan Carrera²**

Presenter: David Lorenzo

Parallel Session I, Room 8

One of the current debates in Genetics is the genomic sequencing in newborns. Thanks to the genomic technologies, it is currently possible to detect diseases that a newborn may suffer in the short, medium or long term.

Genomic tests pose some important ethical issues. Those issues can be classified in three different types: those regarding the object of the screening (genes that must be analyzed), those related to the information (how it must be managed) and those regarding justice questions (economic costs, population to be included in some screening programs).

This study is based on a previous study whose aim was to present a general view of those three ethical problems. This study aims to focus on one of these three problems: the information. We think that how to manage the information on the results of a genomic sequencing in newborns is perhaps the most important ethical issue in this topic. Hence this work aims to address these questions regarding information on genomic sequencing: How the genomic screening has to be explained to the parents in order to get the informed consent? Should the physician give them all the data or only the information related to some genes about which he is sure that they will cause a disease? How the genomic information has to be managed? Can we keep this information once we have finished the screening of a newborn? Should we destroy it after the screening? Is it ethical that parents, without a prescription or medical control, can do on their own a genomic screening on their newborn child?

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MORAL OR ETHICAL EXPERTS? THE ROLE OF BIOETHICISTS IN A DEMOCRATIC SOCIETY

Paweł Łuków¹

Presenter: Paweł Łuków

Parallel Session II, Room 5

It is often believed that if bioethicists are to play the role of experts, the nature of their expertise must be explained and the authority of their advice justified.

This presentation will be a moderate challenge to this view. It will be contended that the nature of bioethical expertise and the source of bioethicists' authority depends on the kind of advice that is expected from them. If one expects a moral advice, i.e. a self-standing instruction about what to do in a given situation, it is indeed hardly possible to identify a moral expert in a rational way, and so to take their advice as authoritative. If, however, the counsel sought is to be an ethical advice, that is, a recommendation guided by a particular normative context, bioethicists can be sufficiently good experts and their instructions can enjoy a significant authority. Since bioethics is a field of research and social practice which developed in a democratic society, the bioethicist's advice presupposes the normative framework of the values and ideals of democracy such as mutual recognition and respect, liberty and equality.

Accordingly, although a bioethicist is not to be expected to be a moral expert (this role belongs, for example, to spiritual or religious leaders), she can be an ethical expert, who – on the ground of her knowledge of the values and ideals of a democratic society, ethical theory and, among other things, social theory and law – can offer a reliable advice which addresses a particular problem.

The expert status of a bioethicist and the authority of her advice derives crucially from the values and ideals of a democratic society and her ethical knowledge, rather than from a moral insight into a realm of context-independent values.

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READING THE MINDS OF YOUNG PEOPLE FOR THEIR OWN GOOD – THE ETHICS OF DIGITAL PHENOTYPING FOR MENTAL HEALTH IN SCHOOLS

**David M. Lyreskog¹, Gabriela Pavarini², Edward Jacobs²,
Vanessa Bennett², Ilina Singh²**

Presenter: David M. Lyreskog

Parallel Session II, Room 7

Across the globe the phenomenon of digital phenotyping – the collection and analysis of digital data for mental health – is growing increasingly popular within the education sector. Schools enter collaborations with health care providers, often with the aim to support young people and to reduce the risk for severe mental health challenges, self-harm, and suicide. In developing technologies for these purposes, algorithms and artificial intelligence (broadly construed) could be utilized to provide as rich and accurate data as possible. The data can then be used to flag up at-risk individuals within the system. Despite the increasing interest in digital mental health tools in many educational systems, there has been remarkably little written about the ethical issues that accompany the emergence of digital phenotyping. Arguably more alarming is that almost no research has been conducted on the acceptability and ethics of these technologies in stakeholder populations: we have not asked young people about their values in this context.

In this paper, we present results from a large quantitative study from the UK, showing what young people value and choose in scenarios involving digital phenotyping in schools. We highlight clear discrepancies between what young people value – and how they conceptualize those values – and how the literature describes the ethical implications of related technologies in schools. We argue that policymakers and ethicists urgently need to learn to recognize and respect the moral boundaries of young people.

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RIGHT TO TRY AND PHYSICIAN ASSISTED SUICIDE: SIMILAR OR DIFFERENT?

Andrea Martani¹

Presenter: Andrea Martani

Parallel Session III, Room 7

In the last few years, the debate whether terminally ill patients should have access to experimental treatments without governmental supervision has intensified. The so-called “Right-to-Try” (RTT) doctrine has become popular especially in the United States, where the federal parliament passed a bill allowing such practices. As many other policies concerning patients’ autonomy in end-of-life circumstances, the appropriateness of RTT has often been challenged. In this context, some authors recently put forward the argument that states where it is allowed to request physician assisted suicide (PAS) should also necessarily recognize a RTT. In the authors’ own words: “if states can give a terminally ill patient the right to die using medications with 100% probability of being unsafe and ineffective against his/her disease [i.e. the substances used for PAS], they should also be able to grant terminally ill patients a right to try medications with less than 100% probability of being unsafe and ineffective [i.e. ET]”.

In this contribution, I will question this argument by underlying three flaws in the authors’ comparison of RTT and PAS. First, there is a fundamental distinction in the nature of the choices between the two situations concerning the (un)certainty of their outcomes. Second, the number of actors (and their potential conflicting interests) involved in these two situations is different. Third, the authors’ understanding of the object of patients’ rights in PAS is partially incorrect.

I will conclude by arguing that, although reasons might exist to support RTT, such comparison with PAS is not one of them.

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THE ETHICS OF E-CIGARETTES FOR SMOKING CESSATION: A GLOBAL CHALLENGE

**Cristian I. Meghea¹, Oana Blaga², Marina Dascal³, Teodora Fratila³,
Petru Sandu³, Horatiu Colosi⁴**

Presenter: Oana Blaga

Parallel Session IV, Room 6

Tobacco smoking is especially harmful for women because, in addition to its effects on mortality and morbidity, it negatively impacts pregnancy, reproductive, and health of the offspring. Data from our work in Romania revealed that pregnant tobacco smokers are seeking information and clinical advice related to e-cigarette use as a tobacco cessation approach. E-cigarette use increased rapidly in the recent years in the US and in other countries, including LMICs. The tobacco control field is deeply divided on how to respond to the increase in e-cigarette use. Additional evidence on the ethical issues related to e-cigarette use and tobacco cessation will inform our mHealth and other pregnancy tobacco cessation interventions and will guide future tobacco control policy direction.

The objective of this study is to identify ethical concerns and associated attitudes and perceptions related to e-cigarette use for tobacco cessation during pregnancy among pregnant smokers, their life partners, medical professionals, and other stakeholders. We will interview (N=20) and conduct two focus groups with women who smoke (one focus group, N=10) and women who quit during pregnancy (one focus group, N=10); interview life partners (N=10) of such women; interview ObGyn physicians (N=10) and nurses (N=10); and interview (N=10) and conduct one focus group (N=10) with perinatal educators. Other relevant stakeholders will be also interviewed

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including the leadership of 2035 Tobacco Free Romania, the national Stop Smoking program, the Pure Air consortium, the Romanian Pneumology Society, the SAMAS NGO focused on maternal and child health and rights, and others. With respect to expected outcomes, the proposed application is anticipated to advance understanding of the smokers' and other stakeholders' ethical concerns and associated attitudes and perceptions related to e-cigarettes use for tobacco smoking cessation. The in-depth new knowledge will have a positive impact on the cessation of prenatal and postnatal tobacco smoking and will inform future tobacco control policy directions.

Results will be available and will be presented at the time of the conference.

This work is based on research partly funded through six NIH-funded projects (grant no. K01TW009654, R21TW010896, 5R21TW010896-02S1, 5R21TW010896-02S2, 1R21HD103039-0, 1R25TW010518-01A1).

LOOKING AT OVERTREATMENT IN ESTHETIC DENTISTRY AS A PROFESSIONAL AND BUSINESS APPROACH

**Alexandru Mester¹, Maria Aluas², Roxana Bordea²,
Ondine Lucaciu²**

Presenter: Alexandru Mester

Parallel Session IV, Room 8

Dental practitioners, sometimes, are facing patient's requests to overtreatment care, which in many situations is completely unnecessary or even dangerous/ risky/ disproportionate to the patient's (oral) health state/condition. It can include procedures such as: teeth whitening, removal of amalgam fillings, closing diastema, veneers, dental extractions, root canal treatment, dental implants or fixed orthodontic appliances.

It is known that dentistry practice belongs to two different and conflicting worlds, medical and business. In front of such situations, dentists should decide the right way of doing their job: being a medical doctor and treating patients or doing business and executing exactly what patients are asking for.

Due to these facts, this presentation aims to: 1) identify the main issues related to this dilemma of dentists and 2) offer a better perspective on realizing dental esthetics treatments without jeopardize the oral health of the patient, but also the dentist's profession and professional integrity.

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SYSTEMATIC EVALUATION OF TWO YEARS OF ETHICS REFLECTION GROUPS. CHANGES OVER TIME REGARDING EMPLOYEES' ATTITUDES, USER INVOLVEMENT, TEAM COOPERATION AND THE HANDLING OF DISAGREEMENT

**Bert Molewijk¹, Reidar Pedersen², Almar Kok³,
Reidun Førde², Olaf Aasland²**

Presenter: Bert Molewijk

Parallel Session III, Room 6

Background: Ethics reflection groups (ERG) or moral case deliberations (MCD) are increasingly used in health care as a form of clinical ethics support (CES). ERGs are often evaluated with a focus on evaluating ERG itself yet not on the impact of or change due to ERGs. Within a larger study implementation and impact of ERG was studied with use of various qualitative and quantitative research methodologies. In this presentation we present findings of the quantitative research.

Research question: Are there changes over time after two years of ERG regarding employees' normative attitudes with respect to the use of coercion, user involvement during the use of coercion, team cooperation and the handling of disagreement?

Research methods: Repeated cross-sectional survey at seven wards within three different Norwegian mental health care institutions (T0-T1-T2).

Results: In total, 817 surveys were included in the analyses. Of these, only 7.6 % (N= 62) have responded at all three points in time, while 76.8 % (N= 628) responded only once. Over time, adjusted for ward and profession, respondents agreed less that coercion is a form of care or security. Furthermore, respondents thought they involved patients and their family significantly

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more often in situations of coercion and they reported that the constructive of disagreement within the team significantly improved. More frequent ERG participation seemed associated with a more critical attitude towards the use of coercion and higher scores for user involvement, team cooperation and the constructive handling of disagreement, yet differences between ERG participation were generally small in absolute terms.

Conclusion: Structural participation in ERG seems to contribute to changes in attitudes, user involvement and team cooperation. Studying changes over time and trying to find a relationship between CES interventions and outcome is difficult yet important and need to be further developed in future CES evaluation research.

COMPROMISING CONFIDENTIALITY: WHERE TO STRIKE THE BALANCE?

James Morgan¹, Kirsty MacKay², Ian Thomas²

Presenter: James Morgan

Parallel Session II, Room 8

Patient confidentiality is a central tenet of medical practice, fundamental to ensuring the maintenance of trust in medical professionals. Yet are there any circumstances where a duty of care to others overrides patient confidentiality and allows disclosure of medical information without consent from the index patient? We present the case of a patient with CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy) a progressive, neurodegenerative condition that is inherited in an autosomal dominant manner. Admitted to ICU with a severe Traumatic Brain Injury (TBI), the patient ultimately had withdrawal of life sustaining therapy following discussion with family. The patient never regained capacity following admission and had never disclosed the diagnosis of CADASIL to his daughters.

The question of whether to disclose the diagnosis to adult children and alert them to their potential risk of inheriting CADASIL (the knowledge of which could fundamentally affect their life choices) raises tensions around confidentiality and any duty of care to the patient's daughters. Previously, for inheritable risks, the prevailing discourse gave prominence to patient confidentiality. However, a recent UK court case and professional guidance is challenging this notion. ICU clinicians faced the choice of disclosing the CADASIL diagnosis to the adult children, breaking patient confidentiality or remaining silent so allowing potential harm to befall them and even future generations.

We examine the ethical issues this raises and suggest how clinicians, if faced with a similar situation in future, might proceed.

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BLIND SPOTS RECONSIDERED – EPISTEMIC INJUSTICE IN CLINICAL ETHICS SUPPORT

Aurora Muff¹, Thu Hang Le², Michael Buzzi², Rouven Porz²

Presenter: Aurora Muff

Parallel Session II, Room 1

Conducting ethical case discussions is a core aspect of any clinical ethics support service or work as an ethical consultant in a hospital. Numerous case discussion methods can be used to do this, many of which are based on Beauchamp and Childress' four biomedical principles. Other commonly used types are the 'moral case deliberations' by prominent authors such as Widdershoven, Molewijk et al.

However, based on our practical work as clinical ethicists, and doctoral students in the field of clinical ethics, we would like to hypothesize that most of the methods seem to be in need of philosophical supplementation, especially on the blind spots regarding the is-ought fallacy, i.e. how to relate empirical data to normative conclusions. A further weakness may be found in the inadequate handling of power structures, which may lead to an unjust handling of opinions.

In our talk, we will therefore present Miranda Fricker's conceptual idea of 'epistemic injustice' and we will apply these insights to clinical cases of our everyday practice. Epistemic injustice is injustice related to knowledge. The concept focuses on exclusion and silencing people in public discourse. This silencing leads to a systematic distortion or misrepresentation of one's meanings or contributions and/or to an undervaluing of someone's status in communicative practices.

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We think that this concept has not been considered in clinical ethics thus far, and we would like to discuss whether ethical case discussions should not help to avoid epistemic injustice. If so, then the case discussion methods of our discipline should be adapted accordingly.

ETHICAL CONSIDERATIONS ASSOCIATED WITH THE USAGE OF ICT “SMART HOMES” FOR ELDERLY DEMENTIA PATIENTS (EPwD) IN THE UK

Gia Mukherjee¹, Asim Chatterjee²

Presenter: Gia Mukherjee

Parallel Session II, Room 4

Dementia encompasses a family of chronic-diseases that gradually causes permanent damage to the brain tissue. Its onset disproportionately affects elderly-individuals’ cognitive and motor abilities. Numerous studies have shown that continuous monitorization of the physiological parameters and activities of EPwD is of utmost necessity.

It is commonly accepted that utilisation of Smart-Homes as an instance of Ambient-Assisted-Living technology can facilitate the care of EPwDs and improve the quality of their well-being. Smart-homes allow EPwD to lead independent and active lives. Outfitted with environmental and physiological sensors that allow patients to receive continuous, non-invasive, and seamless healthcare-service while staying in their convenient-home-environments, Smart-Homes can facilitate (1) remote monitoring of elderly patients’ homes and (2) efficient communication with traditional healthcare facilities.

Significant ethical barriers impede the widespread adoption of Smart-House technology. Many Smart-Houses pose threats to the privacy, safety, and autonomy of elderly-residents. Constant dependence on ICT technology may also undermine EPwDs’ independence and leave them vulnerable to feelings of isolation and hopelessness. Acknowledgment and minimization of these ethical challenges are instrumental to boosting acceptance of Smart-House technology and addressing the primary-care needs of EPwDs.

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Although most existing Smart-House platforms fail to accommodate the specific requirements for elderly dementia care, few notable alternatives have emerged within the UK.

This paper will review the effectiveness of Smart-Home technology on current dementia-care platforms in the UK, analyses significant ethical challenges associated with Smart-House technology use, and outline appropriate risk-mitigation proposals. All recommendations will be made in congruence with a public-health prevention-model.

ARTIFICIAL INTELLIGENCE, SOCIAL MEDIA AND DEPRESSION. 'PATIENT' AUTONOMY REVISITED

**Regina Mueller¹, Sebastian Laacke², Georg Schomerus³,
Sabine Salloch²**

Presenters: Regina Mueller & Sebastian Laacke

Parallel Session II, Room 3

Artificial Intelligence (AI) systems are increasingly being developed and various applications are already used in medical practice. This development promises improvements in prediction, diagnostics and treatment decisions. As one example, in the field of psychiatry, AI systems can already successfully detect markers of mental disorders such as depression. By using data from social media (e.g. Instagram or Twitter), users who are at risk of mental disorders can be identified. This potential of AI-based depression detectors (AIDD) opens chances, such as quick and inexpensive diagnoses, but also leads to ethical challenges especially regarding users' autonomy.

The focus of the presentation is on autonomy-related ethical implications of AI systems using social media data to identify users with a high risk of suffering from depression. First, technical examples and potential usage scenarios of AIDD are introduced. Second, it is demonstrated that the traditional concept of patient autonomy according to Beauchamp and Childress does not fully account for the ethical implications associated with AIDD. Third, an extended concept of "Health-Related Digital Autonomy" (HRDA) is presented. Conceptual aspects and normative criteria of HRDA are discussed.

As a result, HRDA covers the elusive area between social media users and patients.

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QUALITY ASSESSMENT OF CLINICAL ETHICS CONSULTATION. REFLECTION ON THE APPLICABILITY OF THE ETHICS CONSULTATION QUALITY ASSESSMENT TOOL

Stephan Nadolny¹, Andre Nowak², Nicolas Heirich², Jan Schildmann²
Presenter: Stephan Nadolny

Parallel Session III, Room 5

Background. Clinical ethics consultation has been implemented in many health care institutions. Different methods exist for their evaluation. In this paper we present findings from an evaluation of 21 documentation conducted 2019-2020 by means of the Ethics Consultation Quality Assessment Tool (ECQAT). The applicability of the instrument was analyzed based on a) duration of use, b) ease of use, c) comprehensibility of the items.

Results. On average, the analysis with the ECQAT takes 11 minutes per protocol. The greatest difficulties in applying the ECQAT arise a) in assessing the counselling-related information and b) in assessing the ethical analysis as well as the recommendations. Here, different demands on the level of detail of the information may lead to different assessments. Furthermore, the transitions of the ethical analysis and the recommendations, which are relevant for the assessment, could not be delimited exactly in parts of the protocols.

Discussion. The assessment of documentation represents a limited part of the quality of ethics consultation. In particular, the quality dimensions of the EQAT do not map communicative elements of process quality, which are essential components (if not the core) of ethics consultations. Moreover, the assessment is strongly depending on the format of the protocols, which, depending on the institution, range from a brief overview of the results to a detailed account. Even in light of aforementioned limitations the ECQAT provides an incentive to improve the process quality of (documented) ethics consultation.

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FROM ACUTE EVENTS TO CHRONIC DISEASE CONDITIONS: AN INTEGRATED MODEL FOR ETHICS CONSULTATION ALONG THE CONTINUUM OF CARE

**Federico Nicoli¹, Alessandra Agnese Grossi², Jacopo Testa³,
Alessandra Gasparetto², Mario Picozzi²**

Presenter: Federico Nicoli

Parallel Session II, Room 2

The Ethics Consultant (EC), where present, is called on to offer a resolution to ethical dilemmas at different times over the course of treatment. However, it is not yet clear under which particular circumstances the intervention of the EC should be requested when chronic diseases occur following an acute event. As part of the treatment of these evolutionary chronic conditions, the pathway is often complex and may involve multiple actors (i.e. departments, hospitals, and others).

The role of the EC is often limited to a single department and to an isolated event. Therefore, there is frequently no possibility to take into consideration all of the options inherent to the entire continuum of care and of their consequences for the patient.

From intensive care units, rehabilitation wards, long-term hospitalization, through to palliative care, the pathway presents important ethical-clinical questions for the patient, for the healthcare team, and for family members. For these reasons, our objective is to develop a model of consultation integrating the EC along the continuum of care. By analyzing a series of cases, we developed an integrated model of consultation allowing the EC to intervene at different subsequent stages of the process.

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Our findings suggest that this model is an effective means to allow the EC to provide support in relation to single events but also to coherently pursue – within a collaborative setting across different departments – a specific course of treatment which is respectful of clinical indications and of patients’ and caregivers’ preferences along the whole pathway.

COVID-19, MEDIA REPORTING, AND THE ROLE OF BIOETHICISTS

Federico Nicoli¹, Paul J. Cummins², Joseph A. Raho³

Presenter: Federico Nicoli

Parallel Session III, Room 4

In the aftermath of the 2014 Ebola outbreak, media coverage was scrutinized for sensationalism, weakness in explaining scientific uncertainty, dehumanization of patients, and lack of contextualization. The current COVID-19 crisis presents an opportunity to assess whether the media learned its lesson. Results are mixed. Early reporting on the origin of COVID-19 in “wet markets” indicates that the media continues to do poorly with contextualization. On the other hand, stories on mortality and the infectiousness of COVID-19 indicate there has been improvement.

The situation remains fluid as COVID-19 threatens to transform into a pandemic at the time of submission. Data from new countries may alter the reported rates of lethality and infectiousness, and media reporting on these changes may or may not be responsible.

The explosion of social media, as a medium to promote reporting, could provide bioethicists a tool to direct the public to reliable stories and criticize inaccurate ones.

Using a bioethics perspective, this poster will critically evaluate the quality of U.S. and Italian news media’s reporting on the evolving scientific understanding of COVID-19 and its contextualization.

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The presentation will employ QR technology to provide links to media coverage of COVID-19 from the U.S. and Italian news media.

After critically appraising the quality of COVID-19 reporting, this poster will consider if bioethicists: 1) should provide comment to the media on pandemics; 2) should correct reporting for the public and 3) have a duty to publicly criticize sensationalism in the media.

USING GOALS OF CARE CONVERSATIONS TO BUILD ETHICS COMPETENCY

Nico Nortje¹

Presenter: Nico Nortje

Parallel Session III, Room 6

Literature indicates that 99% of clinicians believe that timely Goals of Care (GOC) conversations are important. However, only 11% of patients report having had GOC conversations with their providers throughout the trajectory of their disease. Congruent to this, it is reported that only 41% of patients feel that they have received care consistent with their preferences. One can therefore deduct that there is a great ethical gap in how patients are approached by healthcare providers, especially respecting their autonomous decision-making.

As a concept, GOC refers to discussing patients' therapy intent, which is informed by the patients' hope, fears, information preferences, presumed minimally acceptable quality of life, and expectations for their future. Therefore it needs to be an explicit conversation which is personalized to each patient's context and circumstances. Within these conceptual ideas there are a myriad of ethical values which needs to be addressed.

The author will explain how a Goals of Care initiative was started at the hospital where the author is a clinical ethicist and how these interactions with various members of the care team have been used to build ethics competencies of all the members of the care team. This innovative approach has been applauded by the participants for making ethics practical and applicable.

The structure of the talk will focus on basic literature review, discussion on initiative (how it was set up), challenges, lessons learnt, value in ethics competency development.

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ARTIFICIAL INTELLIGENCE, ROBOTS AND BIOETHICAL CHALLENGES

Renzo Pegoraro¹

Presenter: Renzo Pegoraro

Parallel Session II, Room 4

The arrival of digital research, where the object of research is transformed into numerical data, makes it possible to study the world and medicine, using new epistemological paradigms. What matters now is only the correlation between two quantities of data, with no concern for any consistent theory that explains such correlation. Today these correlations are used to predict with acceptable accuracy.

What seems to be the outcome of this new revolution is the dominance of information, a conceptual labyrinth whose most common definition is based on an equally problematic category-data.

The technological evolution of information and of the world seen as a series of data takes its concrete form in artificial intelligence (AI) and in robots. We are now able to construct machines that can make autonomous decisions and coexist with human beings. And in the context of healthcare it is possible to develop diagnostic approach, prescribe medication (see IBM Watson Program) or offer radiosurgery systems like Cyberknife.

Contemporary society presents extremely delicate challenges where the most important variable is not intelligence but rather the little time available in which to make a decision. Here, cognitive mechanisms can have important applications.

A series of anthropological and bioethical reflections can help to understand the challenges in the healthcare field: "Is it clear how this logic of hyper-individualization, governed by the use of artificial intelligence, will undermine the humanistic need for solidarity in this in deeds and mindset, in favor of private relationships between individuals and organizations?" (E. Sadin).

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ETHICAL ISSUES RELATING TO PRENATAL GENETIC TESTING

Adeline Perrot¹, Ruth Horn²

Presenter: Adeline Perrot

Parallel Session I, Room 8

Introduction: Non-invasive prenatal testing (NIPT) is a rapidly developing genomic technology that is constantly widening its scope and opening up new possibilities in reproductive medicine. Ten years after NIPT has been made commercially available, it is increasingly entering routine antenatal care as either a first- or second-tier test. In England, France and Germany, for example, NIPT has been made available free-of-charge as a second-tier test to women with a higher chance of common chromosomal anomalies. The clinical implementation of NIPT carries benefits but also raises important ethical questions. Our project analyses these questions within their specific contexts in England, France and Germany.

Methods: As part of a wider research project, which will involve qualitative methods, we conducted a document analysis to compare arguments about, and regulations governing NIPT in the three countries in: law and policy document; public reports; medical press; academic literature; and media.

Results: Despite the similarities between the three countries to offer NIPT as a second-tier screening tool, they exhibit differences with regard to their public discourses about prenatal genomics, screening policies, the risk-thresholds they use, professional regulations and laws. These differences have an impact on the way ethical issues emerge, and questions about the meaning of health, illness and disability, the scope of public health interventions, social inclusion and exclusion as well as reproductive choice are approached in each country.

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ETHICAL CONSIDERATIONS IN ICU PREPARATIONS FOR VIRAL EPIDEMICS

Cristina Petrișor¹, Sebastian Tranca²

Presenter: Cristina Petrișor

Parallel Session IV, Room 5

Intensive Care Units (ICUs) admit patients with the most severe forms of the diseases, viral ARDS included. Since the 2009 H1N1 influenza outbreak, ICU preparations and triage have been recommended.

The novel COVID-19 clinical picture resembles influenza in terms of organ dysfunction which may start with hypoxemic breathing insufficiency and ultimately, a possibility of evolution towards multiple organ failure. Its current clinical picture is not new for intensivists. However, there are several important differences as far as we know now: there is overall human susceptibility to become infected and nobody can be specifically protected by vaccination. This fact led to large numbers of infected people all over the world, overwhelming medical systems. Almost 10% of COVID-19 infections would be qualified for ICU admittance and ventilatory support.

The main ethical issues in ICUs, in time of viral epidemics are: lack of free ICU beds, free ventilator machines, pressures on providing aggressive treatments for people with low chances of survival, dealing with terminally ill patients, high degrees of burnout in the medical team, reporting errors and inadequate behavior of other medical staff, lack of adequate protective equipment, as well as lack of administrative support. All these facts lead to moral distress and high burnout incidences.

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Administrative preparations, prioritization and triage are important aspects to consider. In conclusion, we all see that the modern world is not prepared enough to face such challenges and from these situations we, all (health care professionals, providers, population and authorities) should learn important personal and professional lessons.

BETWEEN ETHICS AND AESTHETICS – RECEPTION OF GENETIC INFORMATION AND NARRATIVE EXPERIENCE

Raphaël Pfeiffer¹

Presenter: Raphaël Pfeiffer

Parallel Session IV, Room 2

In a clinical context, the communication of genetic information is an event that can give rise to unexpected situations for health professionals. Several empirical studies have shown that, despite being presented with “good” presymptomatic test results, some patients develop negative feelings, depression, which can in extreme cases lead to suicide attempts. Here, genetic information takes full meaning when considered in a personal narrative.

In this presentation, we would like to look at the specificities of this narrative experience in the light of works on the aesthetics of everyday life, with a particular focus on the works of John Dewey. For Dewey, the aesthetic experience is possible in all aspects of people’s daily lives, including clinical experience. In this case, “aesthetics” appears in the sensitive character of an experience rather than in a specific type of object. Through the examination of this thought, we will ask to what extent we can speak of an aesthetic experience when thinking of the communication of genetic information, and how this consideration can help ethical reasoning.

We will begin by examining how the moment of the communication of genetic information to patients by the clinician can constitute a process of defamiliarization of everyday life. This will lead us to look at patients’ accounts of genetic information reception and to analyse how these appear to be more than mere testimonies about the experience of pathologies, but a means by which the patient is confronted with difficult experiences in order to reformulate them.

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ETHICAL CHALLENGES IN MANDATORY VACCINATION AGAINST COVID-19

Miroslav Radenkovic¹

Presenter: Miroslav Radenkovic

Parallel Session III, Room 1

The current COVID-19 pandemic creates unique and unmatched challenges to healthcare system worldwide. For vulnerable hosts such as immunodeficient individuals, older people, and those with additional comorbidities, SARS-CoV-2 infection primary raises high risk of death outcome. The population should be protected from the further distribution of SARS-CoV-2 through contact distancing, the using of protective masks and other hygiene measures, but also through vaccination, since vaccinations are one of the most important primary prevention tools. Therefore, vaccine is anticipated to protect the vaccinated person from severe disease if infected by the specific pathogen the vaccine was targeted against.

On 11th March 2020 the World Health Organization (WHO) declared COVID-19 as pandemic, yet in 2019, the vaccine hesitancy was named by the WHO as one of the top 10 threats to global health. Acceptance of the vaccine is critical to its success and with the rise of the anti-vaxxer movement; continuous increasing public awareness is needed without any delay.

Mandatory vaccination, including for COVID-19, could be ethically justified if the threat to public health is serious, the confidence in efficacy and safety is high, the anticipated utility of mandatory vaccination is superior to the alternatives, but also if the penalties or charges for non-compliance are balanced. Besides, one can argue that vaccination isn't just an individual preference, namely vaccination protects those who can't be vaccinated. So, although vaccine mandates for

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adults may be legal, so far they have been applied restrictively to select groups, such as health care providers, but also in businesses that require in-person attendance, education-related sectors, or in long-distance travel businesses, rather widely enforced.

As for the vaccination hesitancy, the results of majority of studies indicated vaccine safety, efficacy, protection duration, and potential side effects as the most important reasons for COVID-19 vaccination hesitancy. Apart from vaccine-specific concerns, reasons for vaccine hesitancy also included a need for more information, antivaccine attitudes or beliefs, and a lack of trust. Taking into account the need to keep the world population over the herd immunity threshold, a continuous action is going to be expected from public health authorities to maintain trust and reduce COVID-19 vaccine hesitancy.

INFORMED CONSENT IN DENTISTRY – WHEN, WHY AND HOW

Jelena Roganović¹

Presenter: Jelena Roganović

Parallel Session IV, Room 8

For dentists, as well as for other health care practitioners, it is mandatory to obtain informed consent from their patients, implying that a dialog has taken place and that patients understand the risks, benefits and alternatives to rendered treatments.

Having in mind that majority of dental procedures are surgical in nature, leading to irreversible change to orofacial tissues and with the risk of unwanted side effects, well-documented informed consent process needs to be a basic norm in the dental practice. Clinical experience suggests that verbal discussion along with providing informed consent forms may not be enough and that patients response and understanding may improve by adding adjunctive materials like brochures or videos related to planned procedures. Many companies for implants and dental materials supply dental offices with the brochures and pamphlets, mostly for marketing purposes.

Therefore, the use of these materials must be used with caution while objectively discussing other reasonable options. With the increasingly growing phenomenon of dental tourism, an important dentist-patient relationship ethical issues arise. Namely, issues regarding patient autonomy over practitioner choice, patient safety, and optimal care are under constant reconsideration while informed consent has to specify circumstances underlying treatment plan and posttreatment care.

Currently, there is a paucity of information regarding *informed consent in dentistry*, and vital ethical issues associated with recent developments in dental practice need to be addressed in the near future.

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COMMERCIAL MHEALTH APPS AND EXPLOITATIVE VALUE TRADE-OFFS

Leon Rosσμαier¹

Presenter: Leon Rosσμαier

Parallel Session II, Room 7

Mobile health (mHealth) apps are becoming progressively important for primary care, disease prevention, and public health interventions. They promise to empower its users by offering them more independence, better access to health services, and more insight into their health status resulting in better informed medical decision-making and lifestyle changes. Disadvantages of mHealth apps often include a lack of privacy protection, a decrease in personal attachment, and the acceptance of a normative conception of health challenging the user's self-determination.

Privacy, attachment, and self-determination are, alongside health, linked to fundamental dimensions of human well-being. Users of mHealth apps can either accept those disadvantages or abstain from using this technology entirely. Users, therefore, have to trade-off fundamental dimensions of well-being to gain a certain health benefit if they want to use commercial mHealth apps.

This presentation will clarify the values most relevant in this context, focusing on privacy, self-determination, and attachment. I claim that these values imply fundamental conditions of well-being that should not be undermined, especially in the context of health care. I will argue that the value trade-offs users must engage in are an instance of mutually advantageous agreements by which the provider of the app takes unfair advantage of the user. This renders such agreements exploitative. I will discuss the notion of exploitation that I think applies in this case and explain under what circumstances exploitative agreements that come with the use of commercial mHealth apps oppose the empowerment narrative.

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ETHICAL ISSUES IN THE ROMANIAN PHARMACEUTICAL SYSTEM IN THE CONTEXT OF COVID-19 PANDEMIC

**Lucia Maria Rus¹, Simona Codruța Hegheș², Adela Cacovean³,
Ligia Ancuța Hui⁴, Alina Uifălean², Cristina Adela Iuga²**

Presenter: Lucia Maria Rus

Parallel Session IV, Room 5

COVID-19 infection is a disease caused by the new type Coronaviruses family strain, SARS-CoV-2. It was first identified in China's Wuhan City in December 2019. On March 11, 2020, the World Health Organization officially declared the public health emergency with COVID-19 a pandemic. As in the other affected countries, Romania's health care professionals are on the front line. Among them, community pharmacy and clinical pharmacy teams are facing special ethical situations related to issues as: the provision of protective equipment, sudden medicines price rises, a general increased need in pharmaceutical services of the population concerned about COVID-19, a possible shortage of drugs due to the cessation of their import, ensuring on-going provision of pharmaceutical services in the case of significant volumes of staff absences.

Also, as our country goes through the four scenarios of fighting the new coronavirus based on number of declared positive patients, complex ethical issues could appear for the pharmacist. Thus, significant ethical problems can arise due to the conflict between the duty of care that the pharmacist has assumed by saying and taking the Hippocrates oath and the high exposure of infection that she/he and implicitly those close to her/him have in this situation. Critical situation that may occur in the last two scenarios could raise serious ethical problems related to the violation of fundamental rights for health care professionals and implicitly for pharmacists.

The objective of this work is to assess the ethical issues related to the COVID-19 pandemic in the Romanian pharmaceutical system.

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REDEFINING THE DOCTOR-PATIENT RELATIONSHIP IN THE ERA OF ARTIFICIAL INTELLIGENCE – MODERN MEDICINE’S DILEMMA

Roxana Elena Rusu¹, Beatrice Gabriela Ioan²

Presenter: Roxana Elena Rusu

Parallel Session IV, Room 3

Nowadays, the traditional relationship between doctors and patients is changed by the artificial intelligence (AI) and its involvement in the medical act – ranging from diagnosis to therapeutic recommendations or personalized treatment.

The balance in this triangular relationship is hard to find especially in a digitalized world, in which patients have access to unfiltered information that may lead to inaccurate self-diagnosis.

When it comes to the diverse background of a disease, only a doctor will be able to draw the right conclusion. It is hard to imagine that AI will soon be able to recognize problems such as domestic violence or mental illness. Ultimately, this means that AI is only a means to an end and the responsibility of any taken decision lies with the doctor. Doctors are more than decision making machines and the emotional intelligence cannot be replaced, but the advantages of using AI in the medical field are widely recognized and ultimately the goal is to ensure the best care for the patient.

The purpose of this paper is to point out ethical aspects that rise from the involvement of AI in the doctor-patient relationship and to describe the new roles of the doctor and the patient in the era of AI.

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ECONOMICALLY UNSUSTAINABLE DRUGS AND INTERGENERATIONAL HEALTH CARE JUSTICE

Dario Sacchini¹, Pietro Refolo², Antonio G. Spagnolo²

Presenter: Dario Sacchini

Parallel Session II, Room 1

Introduction. The recent introduction of extremely effective drugs in treating diseases, but associated with exorbitant costs raised several issues in terms of distributive justice. However, in this debate justice is widely thought in intragenerational terms. The work will explore the concept of intergenerational health care justice, in particular the argument, often used to justify the introduction of this type of drugs, according to which the vast amount of money spent now will allow to have savings in the long run. The recent introduction of some drugs that are extremely effective in treating diseases but associated with exorbitant costs, raised several issues in terms of distributive justice. However, in this debate justice is widely thought in intragenerational terms.

Methods: A review of key documents on intergenerational justice was conducted, followed by a nonsystematic review of peer-reviewed and gray literature. The existing material was analyzed and a draft manuscript was prepared and discussed. Some experts carried out the revision of the manuscript until consensus was reached.

Results: The concept of intergenerational health care justice has never been well explored. From an intergenerational point of view, the argument – which is often supported by pharmaco-economic evaluations – according to which the vast amount of money spent now for this type of drugs will allow to have savings in the long run is not in itself coherent with the main theories of justice.

Conclusions: Considerations that are extrinsic to the assumptions of the main theories of justice are needed in order to justify the argument above.

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THE ITALIAN MASTER IN CLINICAL BIOETHICS CONSULTATION: 2013-2020 EXPERIENCE

**Dario Sacchini¹, Pietro Refolo², Barbara Corsano², Mario Picozzi³,
Renzo Pegoraro⁴, Maria Teresa Iannone⁵, Vittoradolfo Tambone⁶,
Gian Antonio Dei Tos⁷, Claudio Buccelli⁸, Antonio G. Spagnolo²**

Presenter: Dario Sacchini

Parallel Session IV, Room 6

This work is aimed at critically illustrating the eight-year experience of the Master in “Clinical Bioethics Consultation” (2013-2020). This advanced second-level Master was promoted in 2013 by the Catholic University of the Sacred Heart of Rome, and co-worked by other Italian clinical as well as academic institutions (University Campus Bio-medico of Rome, Insubria University of Varese, “Federico II” University of Naples, Lanza Foundation of Padua, Local Health and Social Care Unit n. 7 (ULSS) of Veneto Region, Treviso; Ospedale San Giovanni Calibita Fatebenefratelli – Isola Tiberina, Rome, and Italian Group for clinical ethics consultation (GIBCE)).

To this aim, it first will discuss two points: on the one hand, an epistemological one, i.e. the justification of the activity of ethics consultant in clinical settings supported by the authors; on the other hand, a pedagogical one, i.e. the identification of the learning needs clinical bioethics gives birth to.

The second part of the work will focus on the experience of the Master, explaining its basic features (objectives, methods, contents, evaluation tools, etc), offering a critical review, and identifying the challenges this initiative has to face in the next future.

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THE WORLD WILL NEVER BE THE SAME ... BUT WILL I CHANGE? ANTICIPATED MORAL CHANGE IN GENERATION X POST-CORONA NARRATIVES

Yashar Saghai¹, Lucia Galvagni², Monica Consolandi³

Presenter: Yashar Saghai

Parallel Session IV, Room 5

In the “Letters from a Post-Corona Future” study, we asked participants to imagine a desirable world after the Corona crisis and their own place within it. In resulting narratives, any imagined that the future will not look like the past, but did they also imagine that their own moral orientation would change, that is, their stance towards what is a good human life, the norms and values deserving respect, and their moral behavior?

To explore what we call “anticipated moral change”, we focused on Generation X participants (born between 1965 and 1980) since they may be sufficiently mature to have a settled moral orientation and feel concerned by the future, yet sufficiently adaptable to envision internal change. A total of 64 letters from 11 countries were examined. We used concepts from narrative ethics and futures studies to investigate whether anticipated moral change was present in the letters, and if so, in what direction. We identified six categories of anticipated moral change, from radical moral innovation to daily behavior change.

We analyzed how these changes were depicted (e.g., metaphors, modals, idiomatic expressions, narrated futures), felt, justified or evaluated. Results consider the forward-looking moral self-perception of participants in terms of daily behavior, emotions, thoughts, self-advice, norms, values, ideals, images, and dreams, thus contributing to a better understanding of prospective moral change in times of health crisis. We further conceptualized two important categories of change: the inclusion of personal change into collective moral change and renewed moral awareness.

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THE CONCEPT OF VULNERABILITY IN AGED CARE: A SYSTEMATIC REVIEW OF ARGUMENT-BASED ETHICS LITERATURE

Virginia Sanchini¹, Roberta Sala², Chris Gastmans³

Presenter Virginia Sanchini

Parallel Session II, Room 3

Background. Vulnerability is a key concept in traditional – as well as contemporary – bioethics and medical ethics (Ten Have 2015, 2016). Within this literature, the concept of vulnerability is mostly defined in relation to autonomy: vulnerability refers to conditions of impaired and/or diminished autonomy (Belmont Report 1979; CIOMS 1991, 1993, 2002; WMA 2000, 2008; Bracken-Roche et al. 2017). Historically, vulnerability has been associated with several categories of agents, amongst which the elderly are paramount. However, no clear and unique conceptualization of vulnerability, when referred to the ageing population, is currently present – especially in domains other than research ethics: some refer to physiological degradation as a defining tenet, some others appeal to autonomy impairment, some others point to loneliness and isolation (Kahana et al. 1995; Slaets 2006; Dodds 2007; Andrew et al. 2008; Sternberg et al. 2011; Clegg et al. 2013). To fill this gap, we examined the meaning, foundations, and uses of vulnerability as ethical concept in the literature of aged care.

Method. Using PRISMA procedure, we conducted a systematic review of argument-based ethics publications in 4 major databases (Pubmed, Embase, Web of Science, and Philosopher’s Index) of biomedical, philosophy, bioethical, and anthropological literature that focused on vulnerability in aged care.

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5,735 results were obtained. Titles and abstracts were all screened. We are now in the process of full articles screening. All included articles will then be critically analyzed.

The results of this analysis process as well as a critical reflection on the results will be presented at the EACME conference.

ETHICAL CONSIDERATIONS AND PRACTICAL IMPLICATIONS IN ROMANIAN COVID-19 VACCINATION CAMPAIGN

Petru Sandu¹, Maria Aluș², Răzvan M. Cherecheș³

Presenter: Petru Sandu

Parallel Session I, Room 1

Besides its undoubtable significant contribution to morbidity and mortality worldwide, the COVID-19 pandemic has had numerous political, social, economic, and public health implications. Vaccination, an already long debated public health ethics theme, has reoccurred in force, as the efforts of the scientific community to curb the pandemic resulted in a viable vaccine less than one year since COVID-19 was declared a pandemic.

High-level, international negotiations dictated states' COVID-19 vaccine availability in the first few months, therefore each national Government had to develop and deploy vaccination campaigns prioritizing certain population categories.

This paper aims to present Romanian COVID-19 vaccination campaign, from its inception to the present days, by focusing on the ethical considerations (e.g. prioritization, coercion, non-discrimination) and their practical implications (e.g. vaccination hesitancy, rates, fake news).

Like most countries in the European Community, Romania has initially adopted a Rawlsian approach to vaccination, prioritizing the older adults and the individuals with chronic conditions. However, unlike other European countries, coercion was not considered in any form (e.g. extended mobility facilities for the vaccinated), more recently incentives such as food vouchers being discussed.

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The impact of these decisions on the vaccination rates and hesitancy are discussed in the context of other European countries examples of vaccination campaigns.

UNDERSTANDING GLOBAL CHALLENGES OF RAPIDLY DEVELOPING TECHNOLOGIES: DIGITAL METHODS FOR EMPIRICAL BIOETHICS

Manuel Schneider¹, Alessandro Blasimme², Effy Vayena²

Presenter: Manuel Schneider

Parallel Session II, Room 2

Since the first successful application of the gene editing method based on the CRISPR/Cas-system, the technology has demonstrated great potential but also sparked a series of ethical concerns. Some of the issues are already known from earlier gene editing debates. However, the possibility of CRISPR to target genes with high accuracy and the easy application that allows a biohacker to experiment with a simple toolkit ordered online have introduced new ethical challenges.

Further, thanks to preprint servers such as bioRxiv, biomedical research results are more and more accessible with little delay after an experiment was conducted. This enables researchers all over the world to participate and conduct their own experiments, making it a global endeavour. Not only does this make it difficult to monitor and regulate the technology but also speeds up the technological development significantly. CRISPR is only one of many examples of recent advancements with potentially high consequences for society at large. We think it is therefore paramount to identify new issues, understand their nature and assess their impact in a timely manner.

In this paper, we propose the integration of digital methods into the toolbox of modern empirical bioethics and demonstrate their potential with two examples: We used 1) crawling and network analysis for hypothesis building, and 2) sentiment analysis to assess the public's attitudes towards CRISPR on Twitter over a six and a half years period.

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A CONCEPTUAL FRAMEWORK FOR THE ETHICAL EVALUATION OF SUPPORTED DECISION-MAKING

Matthé Scholten¹, Jakov Gather², Jochen Vollmann³

Presenter: Matthé Scholten

Parallel Session II, Room 1

Background: Supported decision-making (SDM) refers to all types of interventions support persons with impaired decision-making capacity (DMC) in making informed treatment decisions. It encompasses a wide range of interventions, such as enhanced consent procedures, elaborated plain language and involvement of family, friends or peers in the informed consent process. Empirical research showed that SDM can enhance DMC. The UN Convention on the Rights of Persons with Disabilities, which has been ratified by 180 states parties to date, pronounces in article 12(3) that “states parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” At the same time, medical ethicists and legal scholars have raised the concern that persons with impaired DMC are more likely to become subject to undue influence under SDM arrangements.

Objectives: The aim of this presentation is to provide a conceptual framework to facilitate an ethical evaluation of various forms of supported decision-making.

Methods: Empirically informed conceptual analysis. Various SDM interventions are analyzed.

Findings: It is necessary to distinguish between input, process and output support. Input support involves influencing factors that are negatively correlated

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with DMC; process support involves interpreting a person's preferences and carrying out intellectual processing; and output support involves enabling a person to communicate decisions to others.

Conclusion: Most forms of input and output support are promising, but ethical issues in relation to framing and interpersonal leverage must be addressed. Forms of process support that involve "outsourcing" decision-making capacities are ethically problematic.

OPPORTUNITIES AND RISKS OF SELF-BINDING DIRECTIVES: RESULTS FROM INTERVIEW STUDIES WITH STAKEHOLDERS IN GERMANY AND THE NETHERLANDS

**Matthé Scholten¹, Laura van Melle², Jakov Gather³,
Yolande Voskes⁴, Guy Widdershoven⁴, Jochen Vollmann⁵**
Presenter: Matthé Scholten

Parallel Session I, Room 2

Self-binding directives (SBDs) are a special type of psychiatric advance directive in which service users agree in advance to (coercive) treatment they might later refuse during a mental health crisis. SBDs aim to empower and protect service users by enabling them to state their values and to plan their (coercive) treatment in advance in consultation with the treating psychiatrist. SBDs have been widely discussed in the ethics literature. Topics include ethical issues surrounding competence, revocation and the ethical justification of involuntary commitment and treatment based on SBDs. Little empirical research on SBDs has been conducted thus far. The Netherlands is to the best of our knowledge the only country with explicit legal provisions for SBDs. On the 1st of January 2020, the new Dutch Law on Compulsory Mental Health Care (*Wvvggz*) entered into force. The implications of this law for the use of SBDs are still unclear.

In this presentation, we will present insights from a qualitative interview study on stakeholders' experiences with SBDs under the new law and their views on the ethical opportunities and challenges of SBDs. Based on the results, we give recommendations for the implementation of SBDs in other European countries.

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THE ROLE OF RESEARCH ETHICS COMMITTEES: MAKING A FAIR OFFER

Mark Sheehan¹

Presenter: Mark Sheehan

Parallel Session IV, Room 4

In this paper, I engage with the on-going debate about the nature of the task that research ethics committees (RECs) have in coming to assess the ethics of research proposals. Some have argued that the role of RECs is to protect participants from harm in the context of researchers who want to benefit future people. Others have argued that the role of RECs is primarily to ensure that potential participants are provided with full information – enough to make an informed choice. On this later view, RECs protect choice rather than restrict it.

I argue that both of these orientations are mistaken and that the role of RECs more akin to a societal overseer who ensures that the research is worthwhile and, most importantly, that it presents a fair offer to potential participants.

On this view, the REC's role is to balance potential harms to participants with the potential benefits of the research in the context of presenting the choice about whether to participate to potential participants.

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MEDICAL REFUSAL: ETHICAL APPROACHES AND ISSUES FOR THE DIFFERENT SIDES OF THE CONCEPT

Andreea Iulia Someșan¹

Presenter: Andreea Iulia Someșan

Parallel Session IV, Room 2

The bioethics analyzes and proposes ethical principles for the biomedical field. In major lines, we can consider the bioethics as having two important branches: biomedical research ethics and clinical ethics. The ethical approaches for each one of the mentioned contexts will bring different recommendation for the involved health professionals.

In the clinical context, the medical refusal may come from the following sides: the patient's refusal for certain prescriptions, the medical doctor's refusal to accomplish some kinds of patient's requests and medical refusal based on medical resources that can be allocate to one patient. What ethical principles and values may have these three sides of the medical refusal?

The aim of the present paper is to evaluate the impact that each one of them may have on the relationship between the attending physician and the patient concerning their common goal, established at the beginning.

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WHEN SOCIETY OWNS MY BODY... ETHICAL PERSPECTIVES ON KNOWING IN ADVANCE POSSIBLE HEALTH ISSUES AND THE EMBODIMENT

Andreea-Iulia Someșan¹

Presenter: Andreea Iulia Someșan

Parallel Session II, Room 7

Living in today's society was presented by some philosophers as an imperative to assume risks that the humanity is still not able to handle. Hence one important question that we may ask is: living today is indeed more dangerous than in the previous centuries?

Presenting the advancement of the biotechnologies as an apocalyptic danger that will surpass the human capacity of management is a perspective not entirely accurate. Medical literature highlights the decrease rate of morbidity in the last decades by some diseases due to medical advancement. Therefore, a balanced view of living in today's society would also point the possibility to know in advance the emerging health dangers and even to calculate their percentage. Nowadays, a patient is supported from the moment when a medical investigation reveals potential health issues. The new body regulation policies induce changes in the social apperception of health and disease.

There is a slow slippery slope from the approach on the individual as a sick person just in case of having symptomatic manifestations and our times when some preconditions of the disease are detectable in medical laboratories. Are we aware about the ethical aspects of treating the carrier of a non-manifested condition as an already sick person? Society also promotes a discourse of non-discrimination and inclusion. Where can we find a balance in the context of the medical advancement?

The present study is a philosophical dialectical approach on the ethical issues of the embodiment in the era of new medical biotechnologies.

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ALLOCATING RESOURCES IN CANCER CARE DURING PANDEMIC. FINDINGS FROM A QUALITATIVE INTERVIEW STUDY WITH ONCOLOGISTS AND ETHICAL ANALYSIS

Sabine Sommerlatte¹, Anna-Lena Kraeft², Celine Lugnier², Anke Reinacher-Schick², Jan Schildmann³

Presenter: Sabine Sommerlatte

Parallel Session II, Room 6

Allocation of health resources towards the treatment of patients with COVID-19 may affect the quality of care for non-COVID-19 patients. Several medical societies representing cancer health professionals have issued statements on priority setting in cancer care in the wake of the Sars-CoV-2 outbreak (1, 2). However, there is a lack of empirical data on how resources are prioritized in cancer care and which criteria are taken into consideration by those involved in decision making.

In this paper we will present findings from qualitative interviews conducted with oncologists in Germany between February and July 2021. Transcripts of interviews are analysed following principles of qualitative content analysis based on Kuckartz (3). According to preliminary analysis of the first five interviews conducted three major topics emerge:

1. Experiences with scarcity regarding selected diagnostic procedures and treatment.
2. Material and procedural criteria for priority setting and decisions on deviations of standards of care.
3. Effects of priority setting on coping and psycho-social support.

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We will discuss findings with regards to their possible contribution to an empirical and normative founded guidance for priority setting in cancer care in times of Sars-CoV-2 outbreak and comparable events.

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LIVED SOLIDARITY IN THE AUSTRIAN HEALTHCARE SYSTEM. HEALTHCARE WORKERS' SOLIDARISTIC PRACTICES WITH REFUGEES

Wanda Spahl¹, Barbara Prainsack²

Presenter: Wanda Spahl

Parallel Session III, Room 3

Disadvantaged groups, such as migrant patients facing language and cultural barriers, often have a harder time getting medically necessary services. Drawing upon data from interviews with, and observations of, healthcare workers in Vienna, Austria, we suggest that they play an important role closing structural gaps within a solidarity-based healthcare system. In our analysis of the lived solidarity of healthcare workers we found three different types of practices:

First, by practices that we call concretising solidarity, healthcare workers act as the mouth, ear, and arm of a solidarity-based healthcare system. They shape solidaristic institutions through their everyday practice. Second, they fill gaps left open by institutionalised solidarity in the healthcare system. Such practices of compensating solidarity become an inherent corrective to the system. A third form of lived solidarity, creating solidarity, goes one step further by trying to create new rules that change the existing norms and instruments (new laws, but also new criteria for the allocation of resources, etc.).

We argue that paying systematic attention to these practices of lived solidarity can help us to improve healthcare services and to ensure that they do not leave disadvantaged and marginalised people behind.

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ETHICS OF HOME MONITORING DURING THE CORONA CRISIS: PROMOTING PATIENT EMPOWERMENT? LESSONS FROM THE PANDEMIC

Jona (J.) Specker¹, Ineke (L.L.E.) Bolt²

Presenter: Jona (J.) Specker

Parallel Session I, Room 7

The development and use of home monitoring or remote patient monitoring has rapidly evolved due to scaling down of face-to-face patient care during the corona pandemic. Home monitoring systems for Covid-19 as well as for other conditions are proliferating. One of the stated goals of home monitoring systems is to promote patient empowerment. However, this concept is hardly well defined and often used in a rhetorical way.

In this presentation, we will discuss the findings of our empirical study into the views of patients, healthcare professionals and policy makers regarding patient empowerment. We report on the results of two case studies of home monitoring systems in the Netherlands implemented during the corona crisis, in which we study, first, what patients, healthcare professionals and policy makers understand patient empowerment to be, and second, whether they think patient empowerment is actually promoted in these contexts. Finally, we will describe different interpretations or degrees of patient empowerment – compliant, concordant, and collaborative - and normatively argue for home monitoring systems that promote optimal patient empowerment.

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DECISION-MAKING ETHICS WITH REGARD TO LIFE-SUSTAINING INTERVENTIONS: SUMMONING WHAT OTHER PATIENTS CHOSE

Anca Sterie¹, Eve Rubli Truchard², Ralf J Jox²

Presenter: Anca Sterie

Parallel Session IV, Room 7

Health decisions occur in a rich context in which social influences are omnipresent. The tendency to compare oneself with others has been described as one of the critical social factors influencing decision making.

Based on a collection of 43 audio-recordings of hospital admission encounters which were analyzed through a conversation analytic methodology, we present findings and reflections in regard to how patients and physicians discuss cardiopulmonary resuscitation. The phenomena of interest concerns how and when patients and physicians refer to what other people decide (for example: “Often the patients tell us: No futile care”). This practice is encountered in 6 of the conversations recorded. Reference to other people’s decisions is a way to talk about options, but it does much more than just enumerating them. As a resource in interaction, this reference is employed when the patient can’t or doesn’t express a preference (thereby clarifying options) or when the preference the patient expressed is problematic (because contrary to expectations). By using this reference, decision making is projected as a matter of membership to a group of individuals, and not as a matter of individual prognostic. The ethical implications of referring to other people’s choices are significant, since it can influence the patient and pose a serious threat to autonomous decisions.

We argue that findings such as ours, stemming from data-driven studies of healthcare communication, are pivotal for informing ethics education in its effort to address the biases that physicians impose upon patients during decision making.

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HOW TO TRAIN AND ASSESS THE QUALITY OF FACILITATORS FOR MORAL CASE DELIBERATION? EXPERIENCES WITH AND EVALUATION OF SELF-REFLECTION AND OBSERVATION FORMS FOR FACILITATORS OF MORAL CASE DELIBERATION

Margreet Stolper¹, Bert Molewijk²

Presenter: Margreet Stolper

Parallel Session IV, Room 7

In Europe, Moral Case Deliberation (MCD) has been well-known and established as a form of Clinical Ethics Support (CES) and implemented in many international (health care) institutions.

Since 2007 Amsterdam UMC organizes training for professionals to become a facilitator of MCD. To support and assess the development of those future facilitators MCD, an instrument has been developed which can be used by both trainees and trainers. The instrument consists of a self-reflection form and an observation form. Both forms are almost identical and contain a part of open questions reflecting upon the personal learning goals of the trainee and a part of 56 closed questions. The part of closed questions contains concrete descriptions of preferred skills and attitude of the MCD facilitator trainee, related to MCD in general and the specific steps of the Dilemma method and the Socratic Dialogue in particular. Special attention is being paid to concrete actions for fostering a dialogue and deepening the moral inquiry. The instrument can also be used by trained and more experienced facilitators of MCD to reflect upon their acquired skills and attitude, and indirectly on the quality of CES they provide.

In this presentation we will present the instrument and share our experiences in using the two forms in order to train and assess (the quality of) facilitators of MCD. Furthermore, we will present preliminary results of the analysis of more than 1200 forms collected in the past decade from trainings on national and international level.

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EUTHANASIA AND WITHDRAWAL OF TREATMENT IN PEOPLE WITH DISABILITIES AND INTRACTABLE DISEASES: COMPARISON BETWEEN JAPAN AND WESTERN COUNTRIES

Miho Tanaka¹, Satoshi Kodama²

Presenter: Miho Tanaka

Parallel Session I, Room 2

Background: In Japan, groups advocating for people with disabilities and intractable diseases (hereafter “PWDs”) have recently voiced serious concerns regarding end-of-life care policies. For example, when non-partisan MPs announced a draft bill on allowing forgoing life-sustaining treatments (LSTs) in 2012, these groups protested. One group in particular strongly protested against a TV documentary by the Japanese public broadcasting corporation in 2019, in which a patient with a serious neurologic intractable disease died by physician-assisted suicide in Switzerland.

Objective: To present the specific concerns voiced by PWDs regarding end-of-life care policies and to compare debates between Japan and Western countries on the topic. Method: Comprehensive literature review. Results: Several important points emerged. In Japan, PWDs felt that those living with LSTs would consider it a life without dignity. In Western countries, the following issues surfaced: negative images of people with disabilities have deep roots in society due to the long and tragic history of discrimination; people with disabilities might become victims of society’s value judgment, such as “life with a severe disability is not worth living”; and laws and safeguard policies cannot eliminate the concerns of a slippery slope.

Conclusion: Western countries have recently discussed the risks of legalising euthanasia, while discussions in Japan have focused more on the risks of legislation on forgoing LSTs. Future literature review studies and interviews with advocacy groups aimed at identifying similar situations in other East Asian countries are warranted.

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CASE STUDY OF THE MORAL DILEMMA: ORTHODOX CHRISTIANITY VS. NEW REPRODUCTIVE TECHNOLOGIES

Roman Tarabrin¹

Presenter: Roman Tarabrin

Parallel Session III, Room 2

Contemporary Health Care poses a lot of challenges, which sometimes are incompatible with the maintenance of the Christian faith. The report aims to analyze the discussions in the Russian Orthodox community to find the solution to the question: Does the participation of Orthodox infertile couples in Reproductive technologies (e.g. In Vitro Fertilization - IVF) coordinate with traditional Christian morality?

Nowadays the Orthodox community is divided into conservatives, who are totally against being involved in IVF, and liberals, who suppose that some of the variants of IVF are admissible.

The report provides an analysis of bioethical issues of Reproductive Technologies from the Orthodox point of view. The author posits that the dilemma discussed is false. It's possible to avoid grievous ethical problems while using IVF. All of them are not equal. Some aspects are absolutely inappropriate. Others, falling short of the mark but not too far, still might be permitted due to the dispensation to a suffering person.

The author discusses conservative and liberal arguments, which were articulated in the International Congress of Orthodox Doctors (2015) and at a panel discussion of Inter-Council Presence of Russian Orthodox Church (2017 – 2019). Cases of Orthodox infertile couples counseled by the author will show the need for some flexibility in resolving these issues. In the report the following cases of

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counseling will be discussed: A) Surrogacy in case of Snow Flakes Adoption); B) Ectogenesis – growing embryos and fetuses in artificial wombs; C) Cryopreservation of embryos; D) the use of IVF in secondary infertility.

The work was done within the project of the Russian Science Foundation “Problems of bioethics in the historical context and socio-cultural dynamics of society” (№ 18-78-10018), carried out based on FSBEI HE PRMU MOH Russia.

THE CHALLENGES OF MULTICULTURALISM ON INFORMED CONSENT IN CLINICAL RESEARCH

Joseph Tham¹

Presenter: Joseph Tham

Parallel Session IV, Room 4

The UNESCO Chair in Bioethics and Human Rights held its 6th international workshop to discuss the issues of Informed Consent and Clinical Research. Being part of the i-Consent consortium, a project funded by the European Union's Horizon 2020 research and innovation program, the workshop focused on the multicultural and interdisciplinary dimension of ethical requirements of informed consent applied to translational/clinical research. Bioethical experts from Buddhism, Confucianism, Christianity, Hinduism, Islam and Judaism discussed the key challenges and the requirements of informed consent in clinical research. Some of the ethical gaps, barriers and challenges present in obtaining informed consent from patients/ subjects in different, challenging cultural contexts were identified, as they represent minority groups and vulnerable populations. One of the findings is that many religious traditions do not accept the Western idealization of the autonomous self and prefer a more relational or communitarian understanding of doctor-patient/ researcher-subject relationship. Western medicine and its current gold standard of informed consent that is practiced globally may not adequately address the theoretical skepticism towards the underlying principle of autonomy by different religions and cultures. This tension is becoming more pronounced with migrant and minority groups when they are asked to participate in clinical research as well as doing research in different parts of the world.

A swift from individual to relational autonomy may offer a more nuanced improvement of the readability, design and obtaining process of consent forms. This shift will take into consideration the conscious and unconscious

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cultural biases of the investigators; multicultural and religious variables of the subjects' understanding; cross-cultural vision of vulnerability, knowledge, communication and empathy; the need for individualized approaches to promote health protective behaviors; and framing questions for a multi-layered informed consent which includes East/West – North/South perspectives.

BEST INTERESTS DECISIONS IN CLINICAL PRACTICE: REVIEWING THE CURRENT EVIDENCE

Emanuele Valenti¹

Presenter: Emanuele Valenti

Parallel Session IV, Room 1

'Best interests' decisions are often needed when patients lack capacity to make their own healthcare decisions. Despite the ubiquity of 'best interests', there remains considerable ambiguity about what best interests are and how the standard should be applied, alongside a lack of understanding about how best interests decisions are actually made in clinical practice. Balancing Best Interests in Healthcare Ethics and Law (BABEL) is an interdisciplinary project, funded by a Wellcome Trust Collaborative Award, which aims to explore best interests decision-making in healthcare, both empirically and normatively.

In this paper, we outline initial findings from a narrative review that asked, 'what evidence do we have about how best interests decisions are made in clinical practice in England and Wales?'. Data were extracted from included papers using a standardised form, and then subjected to thematic analysis, focussing on what the papers told us about the process of decision-making, the stakeholders involved, the barriers and facilitators.

Early results suggest we have some limited evidence about how best interests decisions are made in clinical settings, and the majority of this evidence concerns mental health and end-of-life care. Common factors taken into account in these decisions include: the patient's clinical circumstances; risk assessment; the patient's wishes; cost-effectiveness; avoiding harm; the patient's well-being; autonomy; capacity assessment; and family's wishes.

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THE DIGI-TABLE METHOD AS A TOOL FOR REFLECTING ON RESEARCH ETHICS

Wim van der Molen¹, Els Maeckelberghe²

Presenter: Wim van der Molen

Parallel Session I, Room 6

The Digi-Table Method (DTM) was developed as a tool to visualize abstract concepts and processes by means of a digitable. It is a tool for familiarizing users with complicated and complex issues, learning content, and addressing the more methodical aspects didactically.

In this project, we have adapted the DTM for reflecting on research ethics, i.c. research with human beings and its ethical requirements and the review by the medical ethical review committee (MREC). A MREC reviews research proposals based on various (ethical) requirements and requires researchers to understand the ethical consequences and societal impact of their research. Before writing their own proposals, it is important for students to know and understand these ethical requirements and the process through which research proposals are reviewed. In order to train this, we prepared the digitable to simulate the review of a research protocol by an MREC and adapted it into an existing assignment on research ethics for master students. The students were informed of our aim and the use of DTM as an educational tool, and asked for consent. We invited them to critically assess the activity and we ensured participation would not influence their grade. The students reported a better understanding of the medical ethical review and felt it would improve their own work. From the educator's perspective, the quality of argumentation of the review was much improved compared to previous years.

The DTM as an educational tool is now a standard element in different master courses on scientific integrity.

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FOUNDATIONAL ELEMENTS OF AN ETHICAL DECISION- MAKING MODEL APPLIED IN THE BIOPHARMACEUTICAL CONTEXT

Claar van der Zee¹, Tatjana Poplazarova², Veronique Delpire³

Presenter: Claar van der Zee

Parallel Session II, Room 6

We previously described an applied values-based decision-making model and reported on its use in biopharmaceutical research and development (R&D)*. The model, known by the acronym “TRIP &TIPP”, uses company values along with framing questions as part of a five-step process to guide decisions to complex questions. The employees are engaged as moral agents applying values and principles. Their moral intuition is guided by systematic use of explicit framing questions to increase the understanding and clarity of the values and contextual questions to facilitate the practical implementation of solutions. Sometimes these solutions lead to the creation of internal guidelines in the company.

The ethical norms for biopharmaceutical R&D are shaped by the interaction between ethical reasoning and the context of the situation. Several levels of context are relevant here. First, that of the company within society, which is represented by the stakeholders in our model. This societal context is dynamic as societal expectations change over time. Second, the context of the employees within the company: how the company is organized, its mission, vision and values, as well as the capabilities, experiences and beliefs of the employees. Third, the specifics of the R&D question itself, which requires a pragmatic, solution-oriented, bioethical approach. Finally, ethical deliberation leads to evolving company practices addressing science, technology and society changes.

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*Poplazarova T, van der Zee C, Breuer T. Ethical decision-making in biopharmaceutical research and development: applying values using the TRIP & TIPP model, Human Vaccines & Immunotherapeutics, 2020.

DOI: 10.1080/21645515.2019.1700714

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THE VALUE OF PRIVACY IN SMART DEMENTIA CARE: EMPIRICAL AND ETHICAL

Mark Schweda¹, Eike Buhr¹

Presenter: Eike Buhr

Parallel Session III, Room 6

To protect people with dementia (PwD) from harm, smart technologies are developed to monitor their everyday life and activities and to intervene if necessary. For example, such technologies comprise wearables or video sensors that rely on human-machine interaction. In the ethical and political debate, such monitoring devices are usually discussed under the aspect of privacy.

Generally, privacy is understood as a right that entails an active and deliberate control over one's own decisional, informational and topological concerns. In short, the right to privacy is closely connected to personal autonomy. However, this conception raises problems when applied to PwD. Due to cognitive decline, they lose the ability to actively control their own concerns so that it might seem as though they also forfeit their right to privacy. Yet, this contradicts common moral intuitions as well as empirical studies which suggest that PwD value privacy as an important part of their quality of life (Dichter 2016).

Against this backdrop, our contribution explores the "value of privacy" (Rössler 2001) in the context of smart dementia care. First, we determine the limits of common understandings of privacy when applied to PwD. Starting from empirical studies on the subjective experience of PwD, we then discuss how the moral significance of privacy can be spelled out without tying it explicitly and exclusively to autonomy. On this basis, we discuss preconditions of privacy for PwD in smart dementia care settings, formulating recommendations for future technology development and smart dementia care.

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THE TRANSFER OF KNOWLEDGE IN A TRUSTWORTHY DOCTOR-PATIENT INTERACTION: A PHILOSOPHICAL PROBLEM

Monica Consolandi¹

Presenter: Monica Consolandi

Parallel Session IV, Room 1

The effectiveness of medical evidence is largely dependent on the ability to communicate that evidence to the science-users, mostly patients. Like in many fields of science, also in medicine trust is one of the most important components of doctor-patient interaction. Cultivation of patient trust is, in turn, primarily a linguistic activity, subject to linguistic norms and conventions. Doctor-patient interaction has been at the core of a growing discussion during the past few years, especially in the context of innovations in evidence-based methods and related to the applicability of clinical guidelines derived from those methods.

In Italy, this debate resulted in a recent law (n.219/2017), which declares that “the care and trusting relationship between doctor and patient which is based on the informed consent is promoted and enhanced” (art.1) and that “the time of the communication between doctor and patient is a time of care” (art.8). This new kind of perspective on communication between physicians and patients has led to several questions, above all (i) what is the best definition of trust? and (ii) how achieve a trusting relationship? According to a strictly philosophical point of view, it implies how to successfully communicate imperfect evidence and risk to patients who are in a position of epistemic asymmetry with respect to the doctors; it is problematic because it involves a transfer of complex knowledge of risks and uncertainties from experts to laypeople.

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The paper investigates the difficulties in communicating medical evidence associated with risk and uncertainties of diagnosis and treatment.

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Book Reviews

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