E A C M E

FACING DISRUPTION
CHALLENGES TO BIOETHICS
HUMAN RIGHTS AND DEMOCRACY

WARSAW, 14-16 SEPTEMBER 2023

BOOK
OF
ABSTRACTS

Facing disruption. Challenges to Bioethics, Human Rights and Democracy

European Association of Centres of Medical Ethics
Annual Conference

14-16 September 2023

Organized by
Center of Bioethics and Biolaw
Faculty of Philosophy
University of Warsaw
Poland

E A C M E

FACING DISRUPTION CHALLENGES TO BIOETHICS HUMAN RIGHTS AND DEMOCRACY

WARSAW, 14-16 SEPTEMBER 2023

BOOK
OF
ABSTRACTS

KEYNOTE LECTURES

Ethics of emergencies: lessons from the pandemic

David Archard

The response of the UK Government to the COVID pandemic is currently the subject of a major public inquiry. Already the lack of practical preparedness for a major public health emergency has been highlighted. The Nuffield Council on Bioethics, along with others, has consistently emphasised the importance of being ethically prepared. This is important because the Government's mantra of 'being led by the science' signally omitted to take account of ethics. Moreover, such ethical views as were apparent gave priority to a rather crude number counting consequentialism: save lives, protect the economy and key services. This is an approach that, whilst understandable and generally adopted, should not be seen as the inevitable and necessary response to emergencies. It is important to know why such a response is thought justified at the expense of a more considered moral approach that takes account of fairness and rights. To that end, I consider and respond to various arguments for the standard official approach: that urgency demands simplicity; that what matters is only a numerical balance of costs and benefits; that anything goes in an emergency. I also try to show the importance of certain distinctions (e.g. triage and rationing; tragic dilemmas and dirty hands) as well as highlighting the importance of transparency in public decision making even in extreme emergencies.

David Archard is Emeritus Professor of Philosophy at Queen's University Belfast. He has published extensively in applied ethics, political philosophy and philosophy of law, especially on the topics of children, the family, sexual consent, and the public role of philosophy. He has been Honorary Chair of the Society for Applied Philosophy and is its Vice-President. For twelve years he was a Member of the Human Fertilization and Embryology Authority, and latterly its deputy Chair. He is Chair of the Nuffield Council on Bioethics and a Member of the Clinical Ethics Committee of Great Ormond Street Hospital.

Benefit-sharing through post-trial access in low and middle income countries: status and ethical challenges

Rosemarie Bernabe

The concept of benefit-sharing in research has been heralded in the various research ethics guidelines, though terminologies and scope may differ. For clinical trials, benefit-sharing takes in the form of "post-trial access" which, according to the CIOMS guidelines, refers to the responsibility of various stakeholders, including of course the sponsors and researchers, to "make available as soon as possible any intervention or product developed, and knowledge generated, for the population or community in which the research is carried out ...". In spite of the guidelines, post-trial access provision has been exception and not the rule. The presentation will provide an update on the status of post-trial access as reflected in the literature and the possible challenges causing the state of affairs, may it be ethical, political, practical, and regulatory challenges. The presentation ends with some reflections on how to move forward.

Rosemarie Bernabe is professor of research ethics and research integrity at the University of Oslo and an adjunct professor of medical research ethics at the University of South-Eastern Norway. Her fields of interest are research ethics, research integrity, global health and regulatory science, emerging technologies, as well as the intersection of these various fields. To pursue her fields of interests, on top of her contributions in the literature, Rose currently leads several consortia including the following Horizon 2020/Horizon Europe projects: EDCTP project, Improving post-trial access in Sub-Saharan Africa (AccessAfrica), Responsible Open Science in Europe (ROSiE), The Equitable, Inclusive, and Human-Centered XR Project (XR4Human), Beyond Bad Apples: Towards a Behavioral and Evidence-Based Approach to Promote Research Ethics and Research Integrity in Europe" (BEYOND), and Strengthening clinical trial regulatory and ethical review oversight in East Africa (AccessAfrica2). She also leads the NORPART project, Enhancing Ethics and Integrity Capacity in Medical Research and Clinical Practice (ETHIMED), and the Norwegian Research Council project, Developing national and global agendas for the ethics of post-trial arrangements in LMICs during pandemics/epidemics (Pandemic Ethics). Rose's various projects have institutional members from Europe, Africa, Asia, and Latin America.

Democracies in the digital age: What are we protecting?

Barbara Prainsack

My keynote will draw upon the most recent Opinion of the European Group on Ethics (EGE) on Democracy in the Digital Age (2023). I will discuss the substantive arguments that the Opinion makes affect the framing of the very problem that regulation and ethics is supposed to solve. A first argument concerns the notion of democracy itself: 'Thin' understandings of democracy equate it with majority rule. They risk the emergence of 'phantom' democracies that have all the formal elements of democracies in place, but they have lost its soul and spirit. The EGE understands democracy to mean not just a political regime but also the fundamental rights and values that underpin it. Protecting and strengthening democracy in this sense has two specific implications for societies in the digital era: First, it is impossible to make digital infrastructures and services better and 'more ethical' without changing ownership and control over digital technologies. The more public life and public service provision relies on privately owned technological solutions by companies that are not accountable to the public, the more societies are giving up democratic control. Second, fundamental needs and rights of people in the digital age need to be protected in ways that are adequate to changing personal and collective practices. Using the example of privacy, I will show how most of our instruments and approaches to protect this right are still stuck in the paper age, and how we could do better.

Barbara Prainsack is a professor at the Department of Political Science at the University Vienna, where she also directs the Centre for the Study of Contemporary Solidarity (CeSCoS), and the interdisciplinary Research Platform "Governance of Digital Practices". Her work explores the social, ethical, and regulatory dimensions of genetic and data-driven practices and technologies in biomedicine and forensics. She holds honorary positions at the School of Social and Political Sciences at the University of Sydney, at the Department of Global Health & Social Medicine at King's College London, at the Centre de recherche en éthique (CRE), University of Montreal, Canada, and at the Centre for Health, Law, and Emerging Technologies (HeLEX) at the University of Oxford. Her latest books are: „Personalized Medicine: Empowered Patients in the 21st Century?" (New York University Press, 2017), and „The Pandemic Within: Policy Making for a Better World" (with H. Wagenaar, Policy Press, 2021). Barbara is also involved in policy-related work, e.g. as a member of the Austrian National Bioethics Commission, and as Chair of the European Group on Ethics in Science and New Technologies which advises the European Commission.

Climate justice and the role of health professionals and ethicists in times of crisis

Petra Verdonk

The world is facing an unprecedented public health crisis. After numerous warnings from climate scientists since 1992 (e.g. Ripple et al., 2021), the IPCC announced that it is officially code red for life on earth (IPCC, 2018; IPCC, 2021). In September 2021, more than two hundred medical journals including the BMJ, The Lancet and the Dutch NTvG published an editorial urging governments to take climate action. Editors stated that only fundamental and equitable changes to our societies will reverse the current trajectory towards unprecedented harm and extinction (Atwoli et al., 2021). As regards the role of health professionals, urgent, society-wide and major adaptations are required in in calling for action, educating the public and preparing the health care system, and creating knowledge on health in relation to the climate crisis cannot be underestimated (Charles et al., 2021). The need to preserve planetary health is grounded in the realization that the health of people, communities and human civilization depend on the state of natural systems (Whitmee et al., 2015) and that ecosystems are on the brink of collapse (IPCC, 2021). In the health domain so far, ethicists have remained rather quiet. However, ethical questions require attention: the health domain needs ethics support with issues of distributive justice, addressing (in)equality and (in)equity, or understanding historical injustice. In this keynote, dr. Verdonk will address health consequences of the climate crisis in relation to inequalities including environmental racism, discuss the concept of climate justice, and address the role of ethicists, health professionals, and academics in the climate crisis.

Dr. Petra Verdonk is trained as an occupational health psychologist and has a PhD in integrating sex and gender in medical education. She works as an associate professor at the department of Ethics, Law & Humanities, where she is the chair of the section Participation and Diversity. Dr. Verdonk is expert in gender and intersectionality in health (care) research and education. She developed a longitudinal pathway diversity in medical education as well as a minor programme Amsterdam Global Health. In 2018, Verdonk has experienced an 'ecological epiphany' and has been involved in climate activism since September 2019, for instance in actions towards pensionfund ABP to divest from the fossil fuel industry (and with success – https://www.reuters.com/business/sustainable-business/dutch-pension-fund-abp-sell-175-bln-fossil-fuel-assets-2021-10-26/), and played a role in stimulating VU University Amsterdam to cut research ties with Big Oil (https://www.advalvas.vu.nl/en/nieuws/vu-amsterdam-breaks-fossil-fuel-industry-mostly).

PARALLEL SESSIONS

**Thinking the end-of-life debate as social learning:
a pragmatist approach to bioethics**

Gregory Aiguier

gregory.aiguier@univ-catholille.fr
Center for Medical Ethics, Catholic Institute of Lille, France

In a context of medicalization of our societies but also of reinforcement of the value of autonomy, questions related to the end of life are often reduced to a set of professional practices or to individual questions. Without minimizing these aspects, we can also consider that the end of life is a matter of social and political issues in that they are rooted in organizational and institutional, cultural, legal and political contexts. The question then arises of the possible construction of a collective position on the end of life. In this presentation, we will develop the hypothesis that the issue of the end of life depends on a social learning that aims to "capacitate" actors via the construction of a collective experience. This hypothesis leads us to question the social debate taking place in France. How does it promote real empowerment of citizens? What are the conditions for citizen participation in the debate? How is the latter emblematic of contemporary issues in health democracy? How does it create tension between the representative democracy that prevails in France and the use of a deliberative approach? Our reflection will lead us to introduce the model of „democratic experimentalism" as a way of dealing with this issue of the end of life.

Good faith, Immunity and Social Responsibility related to dental procedures during the Pandemic Outbreak

Authors: Maria Aluaş[1], Sorana D. Bolboacă[2], Anca-Ştefania Mesaroş[3,] Patricia Ondine Lucaciu[1]
Presenter: Maria Aluaş

maria.aluas@gmail.com

[1] Department of Oral Health, „Iuliu Haţieganu" University of Medicine and Pharmacy Cluj-Napoca, Romania
[2] Department of Medical Informatics and Biostatistics, „Iuliu Haţieganu" University of Medicine and Pharmacy Cluj-Napoca, Romania
[3] Department of Prosthetic Dentistry and Dental Materials, „Iuliu Haţieganu" University of Medicine and Pharmacy Cluj-Napoca, Clinicilor Str., No. 32, 400006 Cluj-Napoca, Romania

Oral health field has been one of the first health sectors where the COVID-19 safety measures had been implemented to prevent infections. But the pandemic demonstrated no patterns in infection transmission, and no one could claim to have control on it. During daily treatments, dentists fear that they will be held liable if one of patients is infected with Coronavirus. The aim of this paper was: assessing the dental doctors understanding toward possible ethical issues raised by dental care during the COVID-19 pandemic. We conducted an observational, cross-sectional, exploratory study based on a survey. The target population was represented by active dentists in Romania from March 11, 2020, to January 31, 2022. Most respondents agreed that all dental personnel should benefit from immunity (72%) and indicated the clinic or office management as an entity responsible for the failure to implement/respect the safety measures and protocols specific to the COVID-19 pandemic (83%). Outcomes show the respondents are aware of the possibility of being sued and not be very surprised to see COVID-19 raised in litigation while the state's immunity and implication for all dental care personnel and not only for dentists.

Interspecies justice in times of the climate crisis

Joanna Andrusiewicz

joanna.andrusiewicz@gmail.com
Center for Bioethics and Biolaw, Faculty of Philosophy, University of Warsaw, Poland

Empirical sciences provide good reasons for accepting the intrinsic moral significance of non-human animals. They also provide strong arguments that animal production - in the broad sense - is one of key factors of both environment pollution and climate change.

Twelve years ago „Zoopolis. The Political Theory of Animal Rights" was introduced by Sue Donaldson and Will Kymlicka. The award-winning book presents a theory of citizenship based on animal rights, seen as an extension of the doctrine of human rights.

In the presentation I will argue that there are strong ethical and ecological arguments that such a theory should no longer be seen as an interesting theoretical possibility, but as the most rational choice and moral imperative for democratic societies in the 21st century. In times of climate crisis, abandoning many of the practices towards non-human animals and implementing the theory of interspecies justice is our moral duty not only to non-human animals, but also to future human generations.

**Climate Change and Sexual & Reproductive Health & Rights.
How ethical is their interaction for Sustainable Development?
A Personalist approach**

Fr. Maroun Badr

contact@marounbadr.fr
Facoltŕ di Bioetica, Ateneo Pontificio Regina Apostolorum, Rome, Italy

The climate crisis affecting the whole planet has a significant impact on human health. Thus, it is not without consequences for Sexual & Reproductive Health & Rights (SRHR). Indeed, SRHR, especially contraception and abortion, which constitute a cornerstone of gender equality in Sustainable Development Goals (SDG 5), play a dual role regarding climate change. On the one hand, they must ensure good health (SDG3) that „strengthen resilience and adaptive capacity to climate-related hazards and natural disasters in all countries" (SDG 13.1). On the other hand, the SHRH will make it possible to contribute to the reduction in population growth, which will turn lead to a reduction in the levels of greenhouse gas emissions. In this presentation, I would like to analyze the interaction of these two aspects basing on the Personalist bioethics' model, to determine whether these SRHS contribute to Sustainable Development for a better future of humanity.

The 'embedded' turn in bioethics:
why responsible AI requires more integrative ethics

Marieke Bak

marieke.bak@amsterdamumc.nl
Amsterdam University Medical Centers, The Netherlands; Technical University of Munich, Germany

Responsible research and innovation requires that different stakeholders join forces to embed ethical considerations in the design of new (digital) technologies. Especially with the rise of data-driven and AI-based medicine, there is a need for incorporating ethics early in the design process. While this is recognized by most ethicists, existing methods differ in their level of 'embeddedness'. For instance, empirical ethics research is highly valuable for ascertaining relevant values and providing recommendations, but this is not always done at the fast pace of the developers. Rather than 'pausing' the development of AI until the ethics have been sorted, as was recently suggested in a high-profile letter, I argue that ethics should transform to a more agile and adaptive practice. This move towards stronger and more real-time integration of ethics in digital health technology development can be called the 'embedded turn' in bioethics, following the earlier empirical turn. In this presentation, I compare the aims of existing methodological paradigms (e.g. value-sensitive design and constructive technology assessment) and suggest that within these methods, the overarching paradigm of Embedded Ethics can be adopted to better promote responsible AI. The argument is illustrated with cases from the fields of wearables and robotics in healthcare.

13

Thinking in times of pandemic: the experience of mourning in nursing homes, between rupture and continuity

Rozenn Le Berre

rozenn.leberre@univ-catholille.fr
Center of Medical Ethics, Lille Catholic University, France

Context and issues. Since the start of the pandemic, the situation of nursing homes has received particular attention, emphasizing the impact of health conditions on end-of-life support and bereavement. Many ethical questions arose there: how to comply with health standards while maintaining a human relationship and trust with people?

Method. The project aims to design training/support modules for nursing homes, from the perspective of a community of care, using the tools of research in human and social sciences. For this, we conducted an exploratory survey within three groups of nursing homes with various dimensions and characteristics. From March to July 2021, semi-structured interviews were carried out with residents and relatives who had gone through bereavement in the last 6 months. Focus groups were also carried out with support professionals.

Discussion and Perspectives. One of the major challenges of our work is to question the way in which the subject of mourning, in particular in the context of a pandemic, makes it possible to address issues relating to living together in the EHPAD. Issues related to mourning and loss question people's living and working conditions. Practices and discourses are also particularly questioned in their meaning and symbolism, in particular through the place and function of ritual practices.

Multilingual integrative review in research on peripheral debates on progress and development in the context of climate crisis – opportunities and challenges

Authors: Katarzyna Bielińska, Karolina Kulpa, Sonia Uribe
Presenters: Katarzyna Bielińska, Karolina Kulpa

katarzyna.bieliska@uw.edu.pl, km.kulpa2@student.uw.edu.pl
Center for Bioethics and Biolaw, Department of Ethics, Faculty of Philosophy,
University of Warsaw, Poland

During an ongoing research project, we address a question: "What is the impact of climate crisis on the discourse on progress and development in peripheral philosophies?" Peripheral debates are those which remain on the outskirts of global knowledge circulation and therefore lack visibility. Historically, philosophical reflection on progress and development has been rooted in Eurocentric perspective. Currently, climate crisis affects global peripheries more than the global core making regional and local debates on the topic particularly relevant. That is why we decided to conduct integrative review of local and regional literature to address this topic. We focus on four regions: Africa, Eastern Europe, Latin America and Caribbean, and South-Eastern Asia.

Despite obvious advantages of applying this method to such research, which is providing unbiased results and relevant insights, it poses also certain challenges. They are connected to, among others, search strategies selection, when substantial part of potentially relevant literature is not included in main scientific databases and published in diverse languages, other than English. During our presentation, on the example of the study under conduct, we will discuss opportunities and challenges of applying multilingual integrative review method in such research.

Disruptive Effects of the Use of Artificial Intelligence in Neuropsychiatry

Eike Buhr

eike.buhr@uni-oldenburg.de
Carl von Ossietzky University of Oldenburg, Germany

AI-based approaches such as machine learning using neural networks are increasingly being used in neuropsychiatric research and practice. They are aimed to enable more precise prediction, early detection and diagnosis. However, the basis of the results obtained with these methods is often no longer readily comprehensible. This opacity of AI-based approaches, raises fundamental question for Neuropsychiatry. For example, one understanding of neuropsychiatry is based on the therapeutic effect of a heuristic doctor-patient conversation, which is largely aimed at understanding the patient's malady. However, as soon as the diagnosis is no longer made in such a conversation, but by an opaque AI system, this understanding is fundamentally challenged. We therefore explore the question of how AIbased expert systems change our understanding of psychiatry and neuropsychiatric disorders. To answer this question, we first conduct expert interviews at the intersection of neuropsychiatry, informatics, and ethics, and then compare these with the results of a literature review. It will become apparent that the use of AI systems has the potential to fundamentally change the self-image of neuropsychiatry. In order to be prepared for this, neuropsychiatry must fundamentally consider what should be understood by diagnosis and therapy, not only against the background of AI use.

Prisoner's hunger strike:
juridical, ethical and deontological aspects

Authors: M. L. Burlando, P. Redaelli, S. Ceruti, C. Rossetti, M. Picozzi
Presenter: Matteo Luca Burlando

burlandomatteoluca@gmail.com
Department of Biotechnology and Life Sciences, University of Insubria, Varese, Italy

The hunger strike is a common form of non-violent protest in prison in-
stitutions. This situation leads to complex problems, for both institutions
and healthcare staff who take care of the striker. The conflict between the
prisoner's right to self-determination and the duty of the State to guaran-
tee his health raises important issues worthy of reflection in many areas.
In this contribution, we address the topic from three perspectives: juridi-
cal, ethical and deontological. From a legal point of view, we examine the
rulings of the ECHR. From the ethical prospective, we examine the advice
of the national Ethics Committees that indicate two different positions
regarding the right to self-determination. According to the first position,
a person deprived of his freedom always retains his right to self-deter-
mination and can therefore decide which health treatments to accept or
refuse. This decision must always be respected. The second position con-
sider justifiable not to respect the subject's decision -under some specific
conditions- because, considering the reasons that prompted him to un-
dertake the hunger strike, the principle of protecting life prevails. Finally,
we analyze the conduct of physicians from a deontological standpoint,
in the light of the guidelines of the WHO, the WMA and the European
national codes of medical ethics.

Ethics of AI: a democratizing approach to the design of New Technologies

Authors: Laura Leondina Campanozzi, Vittoradolfo Tambone
Presenter: Laura Campanozzi

l.campanozzi@unicampus.it
Research Unit of Bioethics and Humanities, Campus Bio-Medico University of Rome, Rome, Italy

AI technologies are among us and it would seem that they are destined to stay there and be increasingly present in our daily lives. This global dimension is expressed through concrete points, capable of creating industrial dependencies, such as the definition of technology standards, the choice of 5G suppliers, the dual dimension of technology products, the capacity for social control, persuasion technologies, and so on. In this context, the notions of 'trust' and 'reliability' are dominating the debate as never before. In order to spread and be effective, new technologies must be able to instill trust in future users and be reliable in performing their functions. Not only consumption but also the real impact of technology on society depend on this.

The present work wants to highlight evidence for the hypothesis that a broad involvement of civil society in the design of New Technologies will increase trust in them and greater compliance of end-users also in the post-marketing phase, which is useful for the continuous improvement of products. At the same time, transparency in the relationship between the technology industry and civil society, an important ethical indicator, would be improved. To this end, we propose the formulation of a bottom-up approach to the design of new technologies that we call 'Bottom-up design of new technologies'.

Ethics issues arisen in the medical care of earthquake victim children: Lessons derived from Ayşe's case

Authors: Fatma Zehra Öztek Çelebi[1], Sultan Göncü[1], Mustafa Volkan Kavas[2]
Presenters: Fatma Zehra Öztek Çelebi, Mustafa Volkan Kavas

z_oztek@yahoo.com, Volkan.Kavas@ankara.edu.tr
[1] Etlik City Hospital, Department of Pediatrics, Ankara, Turkey
[2] Ankara University School of Medicine Department: History of Medicine and Ethics, Turkey

Türkiye experienced an earthquake disaster on February 6, 2023. Including children, the number of fatalities reached 50,000 and the injured 100,000 approximately. Numerous ethical problems arose during medical care given to pediatric patients.

We exemplify and discuss these issues in Ayşe's case. As a 15-year-old severely injured patient, she was referred from the earthquake region to a full-fledged hospital in Ankara. Presenting the course of her treatment as a story, we sequentially pause and highlight the following issues: Respecting the autonomy of minors; children as vulnerable groups; moral injury experienced by healthcare professionals; and allocation of limited resources.

Based on our analysis we conclude that ethical codes should be clear on how to act when the child patient refuses treatment and/or her legal guardians cannot be reached. How to inform minors during emergency response poses uncertainty. Children should have priority in treatment and care, and special health services should be available for them. Reducing their suffering and increasing their quality of life are of particular importance. Moral experiences of healthcare professionals should also be addressed as a factor affecting the quality of care. Guidelines and organization schemes are needed concerning the allocation of limited resources.

To what extent can a spiritual approach to health be a way to make our health systems more resilient?

Jean-Philippe Cobbaut

jean-philippe.cobbaut@univ-catholille.fr
Catholic University of Lille, France

Context. While our health systems have been able to cope with the covid crisis, it has highlighted a number of weaknesses and challenges that health care and health systems must address in order to prepare for and cope with the future.

Hypothesis. As part of an international research program on spirituality in health care, we examined the question of what a more spiritually based approach to health care would contribute. Would such an approach allow for a reform of our health care systems towards greater satisfaction, equity and resilience in the face of the challenges ahead?

Methodology. To test this hypothesis, a Think Tank of about 15 people from different disciplinary backgrounds and holding different academic or institutional positions in health administration was set up. This was followed by a seminar conducted on the basis of the Think Tank's initial conclusions in 2022.

Results. This process resulted in a Position Paper establishing a certain number of findings and formulating a series of recommendations with a view to deepening the ethical and political stakes of this hypothesis.

Why are we arguing about abortion when the world is ending?

Ignacy Dudkiewicz

ignacydudkiewicz@gmail.com
Interdisciplinary Doctoral School, University of Warsaw

Among many, two reasons why we don't respond adequately to the climate catastrophe are: a) in the Global North, we don't consider its effects as actual and a matter of life and death; b) prevention of the threat is associated with huge costs. Both mechanisms are related to the limitations of our (moral) imagination. We're more strongly involved in bioethical issues – such as the abortion (vide: USA and Poland) – or political discussions. I want to consider a controversial hypothesis: Does bioethics become (sometimes and partially) a substitute debate in hands of politicians? Sometimes directly: e.g. people who consider environmental pollution as a „punishment for the abortion." Sometimes indirectly: it offers the feeling that we participate in discussions about important (even of life and death) matters, ignoring the greatest threat. How to transform our moral imagination to see both: „here and now" and also a dark future? Is the abortion debate important when the world ends? What can contemporary moral and social imagination offer people who, as Polish climate activist Dominika Lasota says, are understandable less concerned about the end of the world than about the end of the month? This is the great ethical challenge of our time.

How knowledgeable are Cameroonian medical professionals about bioethical issues, and how willing are they to accept clinical ethics structures in their health facilities? The findings of a survey of doctors and nurses in Cameroon's Southwest region

Authors: Kevin T.J. Dzi[1], Oscaline N. Ndong[2], Elizabeth Zeuko'o[2], Nicholas Tendongfor[2]
Presenter: Kevin Dzi

kevin.dzi@unil.ch

[1] Institute of Humanities and Social Sciences in Medicine, Lausanne University Hospital and University of Lausanne, Switzerland
[2] Department of Public Health and Hygiene, Faculty of Health Sciences, University of Buea, P.O Box 12, Buea, Cameroon

Background. Knowledge of bioethics is essential for hospital workers to act morally when confronted with the many ethical dilemmas that arise daily. Our study's aim was to ascertain the level of bioethical literacy among Cameroonian hospital workers (HCPs), the methods they use to deal with ethical dilemmas encountered in the course of their work, and whether they would be open to the implementation of clinical ethics structures (CES) at their institutions that would aid in mediating complex ethical issues.

Methods. Doctors and nurses in hospitals across Cameroon's Southwest Region participated in a cross-sectional questionnaire study.

Results. Among the 469 participants, 65% of HCPs felt the medical ethics training received in medical school was adequate. 80% wanted more ethics training. 83% of HCPs reported encountering ethical issues regularly. When asked how they resolved ethical issues with patients, most said they consulted a senior colleague or head of department. 37% of hospitals had a CES that handled ethical issues. 80% supported the creation of hospital clinical ethics committees.

Conclusion. Bioethics training is needed for Cameroon Southwest HCPs. Many hospitals in developing countries lack CES to resolve ethical issues. In our study, HCPs were willing that such structures be implemented in their health facilities.

Intergenerational Solidarity in the Coronavirus-Pandemic and beyond – Empirically Informed Ethical Analysis of a Normative Resource for Societal Crises

Niklas Ellerich-Groppe

niklas.ellerich-groppe@uni-oldenburg.de
Division of Ethics in Medicine, Carl von Ossietzky University of Oldenburg, Germany

Intergenerational solidarity functioned as a central normative reference point in public debates on COVID-19. However, in the pertinent public (re-)negotiation of moral relations between generations, the concept was often used in heterogeneous, occasionally contradicting ways. This threatened to obscure its moral-philosophical meaning and compromise its normative force. My contribution analyzes what notions of intergenerational solidarity were applied in public debates on the Coronavirus-pandemic and draws conclusions for the future of intergenerational relations. Starting from a relational model of intergenerational solidarity, I identify three types of intergenerational solidarity in an empirical analysis of the German leading media discourse (n=149) between March 2020 and July 2021: communal care, mutual responsibility, and responsible use of freedom. I then evaluate these notions from an ethical point of view, using four normative criteria of a morally substantial conception of solidarity (openness, malleable inclusivity, adequacy of the contribution, normative dependence). I conclude that the clear attribution of responsibilities and the recognition of its limits are decisive factors for intergenerational solidarity to be an essential resource and reliable normative foundation in further societal crises like global warming.

The Implementation of Technical Innovations in Outpatient Care – Considering Professional Nurses' Moral Attitudes in a Transformative Process

Authors: Niklas Ellerich-Groppe[1,2], Tobias Krahn[2], Mark Schweda[1]
Presenter: Niklas Ellerich-Groppe

niklas.ellerich-groppe@uni-oldenburg.de

[1] Carl von Ossietzky University of Oldenburg, Division of Ethics in Medicine, Ammerländer Heerstraße 114-118, 26129 Oldenburg, Germany
[2] OFFIS – Institute for Information Technology, R&D Division Health, Escherweg 2, 26121 Oldenburg, Germany

In light of demographic aging, the change of familial care arrangements, and the shortage of professional caregivers, innovative technologies appear as a promising solution for eldercare. However, the integration of such technologies often fails because concrete needs and contexts are not sufficiently considered. Especially in outpatient care, empirical information on the moral attitudes and concerns of those involved in care processes in the sensitive domestic environment is lacking. Against this backdrop, we present first results of an interdisciplinary, application-oriented research project that combines technological development and ethical evaluation. Based on a stakeholder workshop and a qualitative content analysis of 20 semi-structured interviews with professional caregivers and cared-for-persons in Germany, we explore moral attitudes towards technologies in outpatient care, ranging from total rejection to naive affirmation. In particular, professional self-images and aspects of domestic and familial privacy and informational self-determination prove to be decisive. Based on a care-ethical discussion of these results, we outline empirically informed and ethically reflected strategies for a successful implementation of care technologies in outpatient care.

Conscientious Objection as a Clumsy Solution

Nathan Emmerich

Nathan.Emmerich@anu.edu.au
Australian National University, Canberra, Australia

For the most part the extensive discussion of conscientious objection in healthcare that has emerged over the past two decades has focused on whether the healthcare professional's right of non-participation can be vindicated and, if so, the proper conditions of its implementation. On the face of it this has been treated as a (first order) moral issue, something that has arguable reached its apotheoses in recent claims regarding the symmetry between objection and provision. Discussions of the referral requirement and the notion of institutional conscientious objection proceed on a similar basis. They are framed as moral questions and most authors' seek to adjudicate them as such. In this paper I argue that conscientious objection is an ethico-political device for managing conflicting, irresolvable and well-founded moral perspectives on some first order ethical issue—such as abortion and VAD—or, more generally issues in which establishing a right of non-participation can mediate the kind of otherwise irresolvable matters that inevitable arise in morally pluralist social contexts. As such, the various ways in which a right to conscientiously object has been articulated and implemented suggest it is a clumsy solution, something that "nod[s] in different directions to maintain overall 'normative optimality.'" (Shapiro 1987)

References

Shapiro, M.H. (1987). Introduction: Judicial Selection and the Design of Clumsy Institutions USC Syposium on Judicial Election, Selection, and Accountability. Southern California Law Review. 61(6), 1555–1570.

Fetonate or fetal newborn? Ethical considerations in the development of the artificial womb technology

Montserrat Esquerda, David Lorenzo Izquierdo, Margarita Bofarull

mesquerda@ibb.url.eu , david.lorenzo@sjd.edu.es, mbofarull@ibb.url.edu
Institut Borja de Bioètica, Barcelona, Spain

In recent decades, several research teams have been working on the feasibility of the so-called „artificial womb technology" (AWT). Very often the ethical debate about AWT has focused on the possibility of „complete echogenesis", that is, extrauterine gestation from the beginning, which at this point is technically impossible.

Current AWT research aims to achieve an incubation environment like the womb at a gestational age in which high mortality and mobility are currently achieved, between 22-26 weeks of gestation. These procedures try to ensure survival by means of an oxygenator connected to the fetal umbilical vessels, like fetal hemodynamic physiology that allows development and maturation like in vivo, for a period of 3-4 weeks, until the time at which survival with current neonatal support is adequate.

At the moment, this technology has not been tested in humans, but the models with animal studies are very advanced, and they mean that it is considered that the possibility of applying it to the human field is close.

Multiple ethical conflicts arise from this new technology, the first of which is to determine what moral, ethical or legal status this creature has. On the one hand, an individual is named as „newborn" when he has left the maternal womb. On the other hand, an individual is called a „fetus" when he has not left the placenta and, therefore, some processes have not still begun development which make the individuals technically seem fetuses.

The present work aims to undertake a critical review of the literature, analyze these questions and propose ethical criteria and guidance to be taken into account in the development of AWT.

Human genome editing, polarisation and 'tribal consensus'

Oliver Feeney

oliver.feeney@uni-tuebingen.de
Institute of Ethics and History of Medicine, University of Tübingen, Germany

This paper argues that many calls for deliberative engagement in the context of human genome editing takes insufficient account of the increasing social and political polarisation and tribalism currently facing science (Collins, 2021). A key example is the rise in anti-vaccine beliefs which can be seen to be connected to a notable erosion of trust in established sources of science and medical expertise over the last number of years (ALLEA 2018). Without taking account of this wider polarisation, the goal of seeking public empowerment and societal consensus on human genome editing may be increasingly limited to some sections of society (some 'tribes'), thereby reducing the legitimacy of the consensus achieved – perhaps now more accurately called 'tribal consensus'. There may be a reasonable objection that, even if these wider issues are real, they are too broad and beyond the scope of the human genome editing context. However, given the implications of how polarised groups can have significant political consequences – as dramatically evidenced in recent years – I suggest that it is increasingly unavoidable. Insofar as human genome technology has the potential for significant societal impact, polarisation and tribalism need to be addressed to an increasing extent in such calls for public engagement.

When algorithms replace or support the doctor: Empowerment vs Responsibilization

Brandon Ferlito

brandon.ferlito@ugent.be
Department of Philosophy and Moral Sciences, Ghent University, Belgium

The increasing use of algorithms in healthcare, particularly in mHealth, has raised concerns about the concept of empowerment and its relationship to responsibilization. Although mHealth is presented as a means of empowering patients and increasing patient autonomy, this narrative seems to be based on a specific interpretation of personal autonomy. In this interpretation, the patient is isolated as the sole decision-maker, independent of others with relevant expertise. However, in the context of healthcare, concepts of relational autonomy, which acknowledge and value the role of others while still respecting the patient as the ultimate decision-maker, are generally considered to be more fruitful. Empowerment through mHealth is an undue euphemism for individual responsibilization if the influence of relevant others is disregarded. Responsibility for one's health can be liberating but also burdensome when relevant contextual factors are overlooked.

To address this issue, I distinguish between taking up responsibility and being held responsible without meeting the criteria for responsibility. The former is in line with autonomous choices, whereas the latter is not. I will consider Marion Young's emphasis on the primacy of collective responsibility over individual responsibility as a mechanism to address this issue. The use of mHealth should not shift the burden of responsibility solely onto the patient but should instead promote collective responsibility and enable patients to make autonomous choices.

This talk is part of the DIME panel discussion organized by Heidi Mertes.

Responsibility Gap(s) Due to the Introduction of AI in Healthcare: An Ubuntu-Inspired Approach

Brandon Ferlito

brandon.ferlito@ugent.be
Department of Philosophy and Moral Sciences, Ghent University, Belgium

It is commonly assumed that in traditional healthcare interactions, healthcare professionals are knowledgeable about the advice they give, and can therefore take responsibility for their advice. An algorithm or an AI-based system, on the contrary, it is held, does not understand anything, but calculates an output based on an input, which works well within certain constraints. When an algorithm or an AI-based system perfects itself by self-learning, the developers have little introspection into the result and the potential flaws in the outcome. This is especially worrisome in the field of healthcare. If neither the AI itself nor the developers can take responsibility for the result of the AI, there is a risk of harms occurring that will not be mitigated, remedied or compensated; there is an alleged responsibility gap. Several articulations and arguments regarding the responsibility gap have been provided. Yet, at present, the literature within philosophical literature engaging with this problem is mainly located within Western (or: Anglo-Saxon) philosophy and is mainly taking high-income countries as points of reference. I aim to broaden the debate by providing an Ubuntu perspective to the discussions on the alleged responsibility gap, focusing primarily on the African continent, but offering insights for other continents as well.

Mental health: a new priority in healthcare and for healthcare ethics?

Authors: Lucia Galvagni[1], Monica Consolandi[2]
Presenter: Lucia Galvagni

lgalva@fbk.eu

[1] Bruno Kessler Foundation, Trento, Italy
[2] University of Trento, Italy

Recently experienced events, as the pandemic, conflicts, migratory movements, and climatic catastrophes, have induced the perception of being dramatically 'faced with the extreme', as Tzvetan Todorov observed (Todorov 1991). What impact do such events have on all of us, on the self-perception of the subject, and on the personality of people of different ages? In a research conducted during the late phase of the pandemic (January - July 2022) with Italian healthcare professionals, mental health has been identified as a main priority in healthcare at the present moment and for future perspectives. This is a scenario that can be considered as an emergency itself within the broader emergency represented by the pandemic. Our presentation i) will reflect on the challenge that mental health may represent for healthcare ethics and psychiatry ethics; ii) will consider which kind of contribution ethics, philosophy, and spirituality could bring within the contexts and the practices of the care of the *psyche*.

'White market' – setting norms on human milk exchanges in modern Europe

Małgorzata Gawrońska

me.gawronska@uw.edu.pl
Faculty of Sociology, University of Warsaw, Poland

Despite being banked, informally shared, or even sold all over Europe, human milk remains unregulated in majority of European Union's Member States. Lack of harmonized rules regarding its handling was identified as an obstacle for human milk banks (entities providing donor human milk for preterm infants) development, which lead to efforts for EU-wide regulation. As human milk exchanges are relatively new practice, social and legal norms regarding it are under negotiation. Unlike other substances of human origin intended for therapeutical use, there is no consensus on how to regulate human milk and existing regulations are diversified.

This paper focuses on the process of normative institutionalization of human milk exchanges in Europe, by investigating the process of both legal and social norms setting. It is drawing on analysis of legislative, political, and expert discourses around European Commission's proposal of Substances of Human Origin regulation including human milk within its scope, as well as interviews with experts (a group holding the discursive power). The paper investigates how human milk itself and its exchanges are framed, valued and what beliefs lay under different regulatory models.

Ethical dilemmas and moral distress among dental students. A literature review

Authors: Bianca Georgiu[1], Maria Aluaş[2], Rouven Porz[3]
Presenter: Bianca Georgiu

biancageorgiu1@gmail.com

[1]Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania
[2]Oral Health Department, Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania
[3]Medical Ethics and Continuing Medical Education, Medical Directorate, University Hospital of Bern, Inselspital, 3010 Bern, Switzerland

Moral distress is a negative emotional response that occurs when we act in ways that are inconsistent with deeply held ethical values, principle, moral commitments or professionalism (Kherbache et al, 2021; Sasso et al. 2015). Dental students often face ethical dilemmas once they start clinical modules and deal directly with patients. Students can feel the pressure related to patients safety, valid consent, negative environment or personal behaviours that could lead to the moral distress. The study's purpose is to identify, describe and summarize previous studies on moral distress experinced by dental students. The specific aims were: 1) to establish how moral distress is perceived by dental students; 2) to identify factors that contribute to moral distress among dental students; 3) to emphasize consequences of moral distress on dental students.

AI model GPT-3 (dis)informs us better than humans

Federico Germani

federico.germani@uzh.ch
Institute of Biomedical Ethics and History of Medicine, University of Zurich

Artificial intelligence has revolutionized the way we create and evaluate information, particularly during the current infodemic, which has had devastating effects on global health. At EACME 2023 in Warsaw, I will present our findings on the ability of individuals to distinguish disinformation from accurate information presented in the form of tweets, and to identify whether a tweet was created by a human or the AI model GPT-3. Our recently published study demonstrates that while GPT-3 can produce accurate and understandable information, it also has the potential to generate persuasive disinformation, making it a double-edged sword in comparison to human-generated content. Furthermore, our results suggest that humans are unable to differentiate between tweets created by GPT-3 and those produced by human users. I will use these findings to discuss the potential risks of AI generated disinformation and explore strategies to improve information campaigns that support global health.

Empowerment Through Mobile Health: Three Problems for Autonomy

Jesse Gray

jesse.gray@ugent.be
Ghent University, Belgium

Direct-to-consumer mobile health (mHealth) technologies are often said to empower users by providing them the *information* they need to take *control* of their health. An empowering sense of control is often understood to entail greater patient independence, in the form of individual autonomy. However, wide variations in health and tech literacy call into question the empowerment rhetoric, as these background skills are necessary to justify the sort of patient independence that is envisioned. Creating empowered patients is further complicated by conflicting messaging, as these tools market themselves as having the accuracy of clinicians, while at the same time providing disclaimers that the information provided is untrustworthy, and that users should seek medical advice from healthcare professionals. Even if mHealth technologies successfully promote patient autonomy, the empowerment rhetoric—and a focus on individual control is highly problematic, as individual and collective interests will often conflict. In cases where this occurs, some individuals will lose control, and thereby be disempowered. The empowerment rhetoric serves to cloak these, and various other issues, and should be replaced with more accurate language that better informs mHealth users.

This talk is part of the DIME panel discussion organized by Heidi Mertes.

Participatory approaches for the development of interventions directed toward immigrant populations in the process of organ donation and transplantation: the Italian experience.

Authors: Alessandra Agnese Grossi[1,2], Massimo Cardillo[3], Mario Picozzi[1]
Presenter: Mario Picozzi

mario.picozzi@uninsubria.it

[1] Center for Clinical Ethics, Department of Biotechnologies and Life Sciences, University of Insubria, Varese, Italy
[2] Department of Human Sciences, Innovation and Territory, University of Insubria, Como, Italy
[3] Italian National Transplant Center (CNT), National Institutes of Health, Rome, Italy

'Diversity, equity and inclusion' are emergent issues in organ donation and transplantation (ODT) in Europe. Studies have emphasized the ethical duty to develop targeted interventions for the prevention of inequities in ODT among the most vulnerable and/or socially deprived populations, including migrant and ethnic minority (MEM) groups. With this purpose, the Italian National Transplant Center (CNT) has initiated a project named FAITH (Fostering And Improving equity, participation and inclusion in Transplantation Healthcare) aiming to adapt communicative, educational and management processes to the specific needs of MEM communities, families and individuals at the three main time-points of the ODT process (i.e., promotion of the culture of ODT among the public, relational processes in ICUs, and relational/educational processes at transplant centers with transplant recipients and, when this applies, their potential living donors). The project contends that interventions should be implemented to target not only MEM individuals but also those who relate with them and the context(s) where these processes occur (i.e., the societal context – focusing on the healthcare system and healthcare organizations – and policies). Participatory research approaches emphasize on the collaborative nature of health-related research, where the individuals from the target groups are active partners sharing power and influence over research processes and outcomes. To enable respect for the core principles underlying participatory research (i.e., inclusivity and democracy), the FAITH project has placed prominence on the need to involve and actively engage all stakeholders (including representatives from MEM and faith communities) at all stages of the research process to enable the subsequent development of truly person-centered interventions adapted to the features of the target groups.

Ethics committees should monitor ethical opinions of healthcare professionals and maintain debates alive during pandemic crisis with risk of large-scale prioritization

Thibaud Haaser

thibaud.haaser@chu-bordeaux.fr
Health and Research Ethics Centre, Bordeaux, France

Late 2021, the emergence of the omicron variant of SARS-CoV-2 put healthcare systems at stress worldwide, raising fears of a possible need for large-scale patient prioritisation for the access to intensive care units in France. Ethical or scientific recommendations were published in France but despite them, debates rose about the possible use of non-medical criteria, especially the vaccination status of patients. In this context, the Ethics Committee of the University Hospital of Bordeaux, France conducted a survey exploring the agreement of Health Professionals regarding non-medical prioritization criteria and addressing the conditions of decision-making in a context of prioritization. In 15 days, 1286 responses were collected. The results showed that the debates were as intense in our institution as in society, and that available ethical recommendations (especially non-discrimination on the vaccination status or on age) were not unanimously supported by our professional community. Beyond quantitative results, we also received reactions from participants who considered it was inappropriate or even shocking for an ethics committee to conduct this kind of controversial study in such a context. This presentation aims to present quantitative results but also to think the role of an ethics committee in a pandemic crisis.

Matters about life and death:
Palliative care communication about medical aid in dying requests, when medical aid in dying is illegal

Pola Hahlweg

p.hahlweg@uke.de
University Medical Center Hamburg-Eppendorf, Germany; Beth Israel Deaconess Medical Center, Boston, Massachusetts, United States

Objectives. Medical aid in dying (MAID) is illegal in Massachusetts, US. Nevertheless, patients might inquire about MAID. This study aims to explore how palliative care providers in Massachusetts communicate about MAID requests and their needs to feel well equipped for such conversations.

Methods. We are conducting a qualitative interview study with n=15 to 20 palliative care physicians and nurse practitioners in Massachusetts asking about their experiences and needs regarding communication about MAID. Data will be analyzed with qualitative content analysis.

Results. Preliminary results from n=8 interviews suggest that palliative care providers in Massachusetts do encounter MAID requests, many focus on exploring and understanding the underlying suffering, and try to offer legal alternatives in order to relieve suffering. The need to be clear about own attitudes (internally) and boundaries (internally and explicitly) was voiced. Furthermore, a need for guidelines regarding legal and communication aspects and for open reflection on MAID within teams were voiced. Final results will be presented at the conference.

Conclusion. The results of this study shed light on how palliative care providers communicate with their patients about MAID, if MAID is illegal, and what needs they experience. The results can inform efforts to improve communication about MAID requests.

Decision-making processes on medical aid in dying: scoping review and qualitative evaluation from multiple professional perspectives

Authors: Pola Hahlweg, Zoe Henning, Claudia Martens
Presenter: Pola Hahlweg

p.hahlweg@uke.de
Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Germany

Objectives. Medical aid in dying (MAID) means supporting a person in hastening their death voluntarily. Despite a trend toward legalization of MAID in many countries, the current medical culture struggles to accommodate MAID. We aimed to explore the current state and needs regarding MAID decision-making processes from multiple professional perspectives.

Methods. In this mixed-methods explorative study, a scoping review synthesized the current scientific understanding of MAID decision-making processes. In addition, qualitative interviews with various stakeholders (e.g. physicians, nurses, psychologists, clinical ethicists) were conducted and analyzed with qualitative content analysis.

Results. The scoping review identified n=111 publications. We found great variety in participants of MAID decision-making processes (sometimes team-based approaches), several process phases (e.g. relationship building, assessment, MAID preparation), a range of decisions to be made by different stakeholders, and necessary communication skills. Preliminary findings from n=29 qualitative interviews showed great variety in the needs of people considering MAID (and others involved) and challenges of appropriately identifying MAID requests and adequately addressing both organizational and emotional needs. Final results will be presented at the conference.

Conclusion. The knowledge gained in this study can structure future research on MAID and inform the socio-political debate and implementation efforts in routine health care.

The disruptive potential of AI in human reproduction

Aurélie Halsband

halsband@drze.de
German Reference Centre for Ethics in the Life Sciences (DRZE), University of Bonn, Germany

The use of artificial intelligence (AI) is already having a disruptive impact on societies that is expected to increase. Likewise, reprogenetic enhancement technologies have been presented as having a potentially disruptive impact on reproductive choice, justice and equal standing (Rueda et al. 2022). The use of AI-based embryo selection in assisted reproduction which is currently the subject of intensive research is therefore likely to be disruptive as well and calls for vigorous ethical evaluation. Important ethical challenges that are being raised by involving AI in embryo selection have already been investigated: Embryologists may lose key skills by delegating embryo selection to AI. These skills are however necessary to ensure the required supervision of AI. Also, using opaque AI to select embryos may cause a slide towards eugenics which has been addressed by a call to refrain from using "black box AI" in this therapeutic field (Afnan et al. 2021). Although these challenges raise difficult questions, I will contend that they are not disruptive for societies. Instead, I will argue that the disruptive potential of using AI for embryo selection is more fundamental: it lies in the risk of marginalizing 'natural' reproduction.

How to build up clinical ethics education

Kenji Hattori

medphilosophie@gmail.com
Gunma University, Japan

Clinical ethics helps us to identify and resolve ethical issues in each specific case with specific circumstances in clinical settings. It is not sufficient for educational institutions that train medical or health care professionals to teach bioethics and medical ethics; they must also teach clinical ethics. The structures of these programs are totally different. The vital challenge of clinical ethics education is not to let learners to know existing ethical theories and principles, but to develop their ability to have insight into the feelings and values of persons involved in each case and contexts. To develop this competencies, we have utilized literary works instead of any ethical textbook. When conducting case studies, which are the main body of the course, we have introduced improvisational applied drama in the form of clinical theater, in addition to the ordinary discussion-based case studies. In clinical theater, abstract, speculative rational thinking skills are powerless, but competencies of close observation of non-verbal expressions, imagination about the feelings and situations, and physical expression skills are more important. Compared to traditional education, students are likely to experience more stress, but their capabilities are definitely enhanced.

The ethics of masking at the end of a pandemic: a Japanese perspective

Kazutaka Hirose

kazutaka@koto.kpu-m.ac.jp
Kyoto Prefectural University of Medicine, Japan

Ethical issues at the end of the pandemic have yet to be adequately explored. I offer a perspective based on the current habits of mask-wearing in Japan. While the Japanese Government explained that mask-wearing and other infection control measures were recommended to prevent the spread of infection, Nakayachi et al. (2020) report that the main reason for mask-wearing is that others are wearing masks.

In May last year, the Government issued a guideline stating that mask-wearing was unnecessary if people could keep their distance from others without talking outdoors. However, Nakata and Takaku (2023) show that most people have not changed their outdoor mask-wearing practices as of early March this year. They also found that around 40% of people choose to wear masks in some outdoor places while thinking it is okay to remove them. This suggests that social conformity, exacerbated by the emergency, continues to affect people's decisions on wearing masks and may coerce people who would not choose to mask, to continue to wear a mask. Considering a care ethics framework, I argue for the importance of pandemic ethics that consider the needs of all citizens with diverse abilities and preferences based on the pandemic phase.

References
Nakata T, Takaku R. (2023). Mask-wearing and willingness to wear masks between August 2022 to the fourth week of March 2023. https://www.bicea.e.u-tokyo.ac.jp/policy-analysis-63/(Accessed 2nd April 2023) [in Japanese]
Nakayachi K, Ozaki T, Shibata Y, Yokoi R.(2020). Why Do Japanese People Use Masks Against COVID-19, Even Though Masks Are Unlikely to Offer Protection From Infection? *Front Psychol*. doi:10.3389/fpsyg.2020.01918.

Autonomy and well-being in patient care: What contribution can philosophical analysis make in cases of conflict?

Anna Hirsch

Anna.Hirsch@lmu.de
Institute of Ethics, History and Theory of Medicine, Ludwig Maximilian University of Munich, Germany

Conflicts between patients' autonomy and well-being are certainly a daily challenge in patient care. Although the two principles of medical ethics that play a role here, respect for autonomy on the one hand and beneficence on the other, are much discussed not only in academic ethics but also in the field of clinical ethics (counselling), the conflict between the two principles is theoretically underdetermined: For neither in academic ethics nor in clinical ethics has it been sufficiently clarified how the obligations of beneficence (and nonmaleficence) on the one hand and respect for autonomy on the other are to be related to each other. Accordingly, the medical ethics literature in this context focuses primarily on the issue of paternalism, whereby nuances and subtleties of the conflict remain unconsidered. In my talk, I would like to show how we can develop differentiated understandings of autonomy and well-being in patient care by drawing on more sophisticated philosophical theories. Differentiated understandings of autonomy and well-being, I argue, offer argumentative support for weighing up conflicting obligations and help to better understand conflicts between autonomy and well-being in patient care.

Navigating ethics in digital health development –
An interview study on stakeholders' perspectives in the German, Indian and US digital health start-up sphere

Authors: Bianca Jansky[1, 2], Ayush Shukla[1, 3], Verina Wild[1]
Presenter: Bianca Jansky

Bianca.Jansky@gmail.com

[1] Institute of Ethics and History of Health in Society, Medical Faculty, University of Augsburg, Germany
[2] Institute for Sociology, Ludwig Maximilians University Munich, Germany
[3] TUM School of Social Sciences and Technology, Technical University of Munich, Germany

Data-driven healthcare technologies are increasingly being introduced into national healthcare policies. These technologies are surrounded by social imaginaries and hopes of creating faster, cheaper, more precise and personalised healthcare for more people. Both in public health and economic discourses, digital health is currently discussed as the solution to offer ways out of underfunded public health institutions.

These hopeful policy narratives foster growing digital health start-up spaces that are emerging around the globe. Here start-ups offer a vast amount of digital and data-driven healthcare technologies, from diagnosing apps to electrocardiograms for smartwatches. Focussing on stakeholder interviews conducted in three countries that are very active in digital health innovation (India, Germany and USA), the aim of this presentation is twofold. Firstly, we will retrace the opinions and moral views of those developing these technologies. In a second step, we use our empirical material to sketch out possible ways for bridging the gap between ethical scholarly discussions about data-driven healthcare technologies and these accounts of the experiences of stakeholders by emphasising that the point of convergence for every technology entering the healthcare sector needs to be the acknowledgement of health as a human right and a specific value.

Relating as equals in the face of limited health resources: analysing allocation guidelines through a relational egalitarian lens

Karim Jöst

karim.joest@med.uni-augsburg.de
University of Augsburg, Germany; LMU Munich, Germany

Recently the Committee of Ministers of the Council of Europe has given their latest recommendation on securing equitable health access in situations of shortage. Conceiving of such situations as purely distributive ones and tackling them with distributive egalitarian or utilitarian theorising, however, is bound to fall short in grasping all relevant justice concerns and in adequately considering (structural and systemic) background injustices and social determinants of health. While relational/social conceptions of justice have gained traction in political philosophy, little has been said about their distributive implications for allocating limited health resources. Situating and assessing relational egalitarianism regarding health justice provides ground to both look back at the distributive theories applied to allocation questions during COVID-19, to identify and address concerns they were unable to grasp, and forward, at the Committee of Ministers' recommendation, evaluating their guidelines from a relational perspective. The aim is twofold: (a) embrace the problem at hand and see if relational theories apply and help provide answers by taking relevant justice concerns properly into account; (b) show what in turn is required of policies to make it possible to relate to one another as equals when it is not possible to satisfy each person's distributive needs.

Fighting loneliness with chatbots? Ethics of self-deception

Emilia Kaczmarek

emilia.kaczmarek@uw.edu.pl
Faculty of Philosophy, University of Warsaw, Poland

Imagine a woman chatting with her AI chatbot. She looks at her smartphone and says: "Finally, I'm being understood". Imagine a man looking into the eyes of his sex robot. The robot says "I want you" and the man thinks: "Finally, I'm being desired". Are these people deceiving themselves? Is there something morally wrong with this kind of deception? And if so – why?

The problem of deception in human-AI emotional relationships has been discussed for years. Various authors would give opposing answers if asked above questions about hypothetical AI-users who felt loved or understood by their devices. Some scholars (Turkle, Sharkey, Sparrow) would most likely answer *yes, these persons are deceiving themselves*. Others (Coeckelbergh, Danaher) would most probably disagree. The problem in question is not purely theoretical. We already have different mental health apps working as a chatbot-psychotherapist (e.g. Woebot) or AI friends (e.g. Replika). It seems reasonable to assume that new transformer language models (such as GPT-3) may speed up this process even more. In my presentation, I want to consider the moral problem of deception and self-deception in human-AI emotional relationships with both robots and chatbots.

Public Health Policy in a Disrupted World: the Israeli Case

Nili Karako-Eyal

ncaracoe@colman.ac.il
The College of Management, Israel

During the last five years, Israel has experienced a multi- dimensional process of disruption. Several factors contributed to the formation of this process, including continuing political instability, protests against the selected government, and the deepening of conflicts between different sectors of the society (i.e., the secular and the religious sectors; Mizrahim and the Ashkenazim; the supporters of the right-wing parties and those of left-wing parties).

The Corona pandemic which constituted a public health emergency, intensified the process of disruption. Political protests criticized the public health policy adopted by the government, claiming that it infringes human rights, harms Israel economy, and threatens public health. Social polarization was also intensified. Religious and Arabic communities were severely criticized, because of their refusal to cooperate with public health guidelines.

Against this background, the paper presents three propositions: first, when a multi- dimensional process of disruption takes place, the potential of the law to execute public health policy is limited. Second, public health ethics and non- legal measures are of special importance in conditions of multi- dimensional disruption. Third, in the planning of public health policy the phenomena of multi- dimensional disruption and its implications should be considered.

Data-driven research and healthcare:
Public trust, data governance and the NHS

Angeliki Kerasidou, Charalampia Xaroula Kerasidou

angeliki.kerasidou@ethox.ox.ac.uk, xaroula.kerasidou@ethox.ox.ac.uk
Ethox Centre, University of Oxford, United Kingdom

Trust is important for the acceptability of data-sharing practices and new technologies in health research and healthcare. Yet there is an increased distrust in this domain. In this paper, we use the UK's NHS as a case study to examine the question of, what it is about sharing public healthcare data for research and innovation that challenges public trust. To do this, we provide an account of public trust to explain the trust-relationship between the public and the NHS within a democratic context. We examine whether the way in which the NHS is managing patient data and collaborations with the private sector fit under this trust-based relationship. We argue that the digitisation of the NHS and the broader 'health and wealth' agenda adopted in the UK represent a major shift in the institutional character of the NHS. This questions the meaning of public good the NHS is expected to provide, challenging public trust. We conclude that a theoretical and empirical examination of the benefits and costs associated with this shift, as well as an open public conversation to determine what values should be promoted by a public institution, like the NHS, are necessary to address the public trust deficit.

Ethical Issues of Deaf People Engagement into Research: A Qualitative Evidence Synthesis

Authors: Tomasz Krawczyk[1,2] , Jan Piasecki[1] , Mateusz Wasylewski[1], Marcin Waligóra[1]
Presenter: Tomasz Krawczyk

tomasz.r.krawczyk@uj.edu.pl

[1] Faculty of Health Sciences, Department of Philosophy and Bioethics, Jagiellonian University Medical College, Kraków, Poland
[2] Doctoral School of Medical and Health Sciences, Jagiellonian University Medical College, Kraków, Poland

Engagement of deaf people into research raises ethical challenges. The research itself is a field of dispute about deafness. Various deafness-related disciplines function rather separately and develop their own epistemologies. Moreover, deaf communities around the world are diverse in recognition of group identities, shared history and faced marginalisation. Despite such a complex situation, normative recommendations on the topic are lacking. Therefore, our study aimed at exploring how to ethically engage deaf people into research. To include the voices of deaf people, we investigated existing qualitative and mixed methods research, conducting a qualitative evidence synthesis. We followed ENTREQ statement recommendations for qualitative syntheses. Our synthesis used two sources: a systematic database search (Scopus, PubMed) based on pre-defined SPIDER search strategy and checking the references of included papers. We analysed the data using thematic synthesis. We focused on the ethical issues present within research process, relations between researchers and participants, opportunities of being involved, as well as research dissemination and its impact on the community, etc. Our research may contribute to enhancing ethical inclusion of deaf people into research. It may also support the development of evidence-informed normative recommendations for ethical engagement and scientific cooperation between deaf people and researchers.

Limiting freedom of movement in residential care for people with dementia - An empirically informed ethical exploration of institutional practices and moral perspectives

Kim Meilin Kulaczewski[1], Aurelija Dagilyte-Drevel[2], Elleke Landeweer[2], Mark Schweda[1]
Presenter: Kim Meilin Kulaczewski

kim.meilin.kulaczewski@uol.de

[1] Department of Health Services Research, School of Medicine and Health Sciences Ethics in Medicine, Carl von Ossietzky University of Oldenburg, Germany
[2] Department of Primary- and Long-term Care, University Medical Center Groningen, The Netherlands

Due to progredient cognitive impairments, people with dementia (PwD) are at an increased risk of getting lost and/or incurring harm. Therefore, care facilities often implement measures to restrict living space and range of movement. However, many of these strategies are controversial and raise moral and legal questions since they concern basic human rights and disrupt quality of life. Although there is increasing discussion of alternative approaches, there has been little research on the actual practice and its moral evaluation. This presentation aims to identify strategies that are currently implemented in care facilities and to discuss them ethically. It is based on an explorative interview and observation study with stakeholders in eight facilities in the Ems-Dollart region. The results reveal a broad spectrum of strategies and moral perceptions that range from focusing on safety and well-being of PwD to emphasising autonomy and freedom of movement. The ethical typology of the different approaches reveals that alternatives to limiting the range of movement are widespread, although there is disagreement about their necessity, efficiency and appropriateness. We critically discuss the persistence of morally and legally questionable practices involving limitations of the liberty of PwD, and propose criteria for the ethical evaluation of alternative approaches.

Polish abortion reality in the eyes of gynaecologists.
Findings of a qualitative study

Antonina Lewandowska

ad.lewandowska2@uw.edu.pl
Doctoral School of Social Sciences, University of Warsaw, Poland

The presentation will explore Polish gynaecologists' knowledge of Polish abortion reality and their medical experiences related to the procedure of pregnancy termination. The data presented will be a novelty, as it was gathered during one of the first Polish qualitative studies focusing on medical practitioners' approach to abortion (conducted in 2022). The analysis includes media coverage relevant to the topic and seven semi-structured individual interviews with gynaecologists. The speaker does not hide her professional involvement in the abortion rights debate, using her work experience as an autoethnographic source of additional data.

The topic of abortion reality will be approached from a constructivist perspective, with analysis rooted mainly in Michael Herzfeld's concept of cultural intimacy and the role of uncertainty in Medical Decision Making as understood by Eric B. Beresford. The presentation will also draw from Jean Baudrillard and his theory of simulation.

Conducted analysis suggests factors such as medical schools curricula, tabooisation of abortion, and abortion legislation to have a strongly negative impact on gynaecologists' attitudes, emotions, professional performance, and mental health. The presentation will therefore tackle issues connected to sociology of medicine and bioethics.

Support with limitations?
Perspectives on AI-based clinical decision support systems

Authors: Wenke Liedtke[1], Diana Schneider[2], Florian Funer[3], Nils B. Heyen[2], Myriam Lipprandt[4], Tanja Bratan[2], Sabine Salloch[5], Martin Langanke[6]
Presenter: Wenke Liedtke

wenke.liedtke@uni-greifswald.de

[1] Theological Faculty, University of Greifswald, Germany
[2] Fraunhofer Institute for Systems and Innovation Research ISI, Karlsruhe, Germany
[3] Institute for Ethics and History of Medicine, Tübingen University Hospital, Tübingen, Germany
[4] Institute of Medical Informatics, Medical Faculty, RWTH Aachen University, Aachen, Germany
[5] Institute of Ethics, History and Philosophy of Medicine, Hannover Medical School (MHH), Hannover, Germany
[6] Protestant University of Applied Sciences Rhineland Westphalia-Lippe, Bochum, Germany

The future use of AI-based clinical decision support systems (CDSS) in medical research and care poses ethical and social challenges for healthcare professionals and patients. These include issues of autonomy, transparency, discrimination, but also questions of distributive justice or responsibility of different actors.

The talk refers to results of an empirical qualitative project on the possible use of AI-based CDSS. Needs and concerns of potential patients were explored in focus groups, future healthcare professionals were consulted in semi-structured interviews. This revealed similarities and differences in the assessment of ethical challenges regarding implementation and use within healthcare.

Against this background, the presentation will focus on the question of responsibility and the uncertainties associated with the different opinions. The results indicate that restrictions of freedom of choice and lack of technical competence function as prominent aspects in the context of attributing responsibility.

Considering the future use of AI-based CDSS, we must therefore ask fundamental questions about the involvement of future actors in care-like healthcare professionals or patients-and their education processes and about the possibility of empowering moral agents to make free decisions within the framework of technology use, but also about how these technologies change the way we think about decision-making.

An Examination of the Ethical, Legal, and Policy Issues on Mobile Medical Apps on Smart Devices in Taiwan

Hung-En Liu

markliu8@gmail.com
Center for Bioethics and Medical Law, National ChengChi University, Taipei, Taiwan

Smart devices with internet connectivity have become essential tools that people almost never leave home without. In Taiwan, among all the mobile apps, the number of mobile health app users has increased the most, mainly because of the convenience of the apps, the easy accessibility and intuitive operation, and the autonomy of users to control their own medical and health conditions. Also, some doctors are positive about these apps because they can help them to track and understand patients' condition for a longer period of time and even link to hospital medical records for big data analyses. However, the widespread uses of the apps may lead to many controversial issues, such as: Are they medical devices and should they be pre-approved? Are the physiological indices they measure accurate, and if not, are they likely to pose health risks to users? Do the medical apps collect users' personal information and share it with third-party entities, and do they obtain prior informed consent from users? How should their uses via the Internet, which often cross national borders, be handled in terms of jurisdiction and application of the law? This paper aims to examine the regulatory system and experience and their problems in Taiwan on these issues, and it will explore some of the experiences from other countries as references for future policy reform in Taiwan.

An Ethical Analysis of the Risk of Transhuman Subspecies and Germline Genome Editing

Larry Locke

llocke@umhb.edu
McLane College of Business, University of Mary Hardin-Baylor, Belton, Texas, United States;
LCC International University, Klaipëda, Lithuania

The possibility of human germline genome editing has produced both tremendous enthusiasm and troubling worries. Genetic scientists have held out the promise that human germline genome editing can help eliminate hundreds of debilitating, genetically-related conditions, such as Huntington's Disease and Sickle Cell Disease. Some of the concerns raised about germline gene editing are equally dramatic, conveying dystopian images of gene editing gone wrong. Unlike somatic gene editing, germline edits are heritable and can become a permanent part of the gene pool over succeeding generations. This potential impact on future generations of humanity has produced many concerns over the potential creation of a new subspecies of human animals. Communitarian critics fear a loss of solidarity that may lead to the introduction of social divisions, which may ultimately result in open conflict. In this paper, we present these arguments against human germline genome editing and respond to them through an application of both categorical and consequentialist theories. We conclude the paper with the claim that categorical theories are unhelpful in resolving this issue but that consequentialist theories may support the use of human germline genome editing.

The Right to Consciencious Objection in Healthcare

Authors: M. Esquerda, J. Bertran, M. Bofarull, F. Torralba, J. Bátiz, V. Cusí,
F. J. Cambra, J. A. Suffo, J. De La Torre, J. M. Velasco, M. Martin
Presenter: David Lorenzo

david.lorenzo@sjd.edu.es
Institut Borja de Bioètica, Barcelona, Spain

In recent decades, euthanasia has been decriminalized or legalized in several countries (the The Netherlands, Belgium, Luxembourg, Spain, Canada, Colombia and New Zealand). The debate on whether or not to legalize this practice is open in many other countries and is a topic that arouses great controversy both at the theoretical and practical level (clinical care).

This debate has reopened or intensified the discussion on conscientious objection, a discussion that is more or less always present in relation to the practice of abortion. Individual conscientious objection is a subject that has already been extensively covered in the literature, although it has now returned to being the subject of discussion: some authors (Savulescu, Schucklenk…) thinks that there is no place for individual conscientious objection in Healthcare of contemporary societies. What happens when an individual, for deep ethical reasons, refuses to apply or develop a practice that the profession and the law accept? Can him refuse? Can this attitude put in danger the rights of a patient (rights recognized by that same legislation)?

This paper aims to answer to these questions by accepting that it is possible to respect the professionals' right to conscientious objection and also the patients' right to receive adequate treatments.

Female genital mutilation and multiculturalism: the limits of cultural tolerance

Emanuele Mangione

emangione@uninsubria.it
University of Insubria, Varese, Italy

Within multicultural societies, medicine is likely to be the scene of cultural clashes. Requests for the female genital mutilation (FGM) are a case in point: since FGM consists in the non-therapeutic injury of the external female genitalia, it goes against most of the ethical principles of medicine; despite that, it is a persisting practice that could be requested on the grounds of culture. The aim of this work is hence to explore whether and to what extent FGM could be tolerated or even medicalized in the name of cultural ethical relativism. First, through an analysis of the literature, a brief explanation concerning FGM and why it could be requested is offered. Second, FGM is compared with other cultural practices, and the need for cultural tolerance is addressed by inquiring about the existence of some moral rules holding for everyone. Third, it is argued that even a symbolic FGM might sound discriminatory or psychologically harmful, and cultural tolerance, while partly needful, has its limits. Finally, an integrated and multiculturally competent approach is suggested.

Ethics of AI-based decision-making in cardiac defibrillator implantation: patient perspectives

Menno Maris

m.t.maris@amsterdamumc.nl
Amsterdam University Medical Centers, The Netherlands

The emergence of artificial intelligence (AI) in medicine has prompted numerous ethical guidelines, while little is known about patients' perspectives on ethical considerations surrounding its use. As part of the PROFID consortium, in which AI-based prediction of sudden cardiac death (SCD) is central, we explore patient perspectives on the ethical implications of AI in high-stakes cardiac care for patients at increased risk of SCD. Semi-structured, futures scenario-based interviews were conducted with implantable cardioverter-defibrillator (ICD) patients and patients at increased risk of SCD in Germany (n=10) and the The Netherlands (n=14). Interviews were based on the European Commission's ethical guidelines for reliable AI enabling us to reflect on said EC guidelines. While patients sympathize with the pursuit of technological innovation in healthcare, they also worry that the introduction of AI will come at the expense of the human touch in medicine. Patients expressed concerns about losing control over decision-making, affecting their perceived autonomy, even if health outcomes would remain the same or improve with the introduction of AI. Patients are not inclined to ascribe autonomous characteristics to AI technology. They emphasize the responsibility of the person behind the technology, both developer and medical professional.

The French Connection:
How One California Based Organization is Transforming
its Locked Mental Health Treatment Facilities
to Optimize Recovery Outcomes

Chris Martin, James Ritchie

chris.martin@cbhi.net, james.ritchie@cbhi.net
Crestwood Behavioral Health, Inc., United States

In a 1793 letter, the superintendent of the Bicetre Hospital in Paris, Jean Baptiste Pussin, advised his director, Dr. Phillip Pinel about the condition of the asylum when he wrote "As much as possible, all servants are chosen from the category of mental patients. They are at any rate better suited to this demanding work because they are usually more gentle, honest, and humane." This promising practice that started in France may have included the world's first peer support specialists, but somehow became largely forgotten about until the late 20th Century.

Now in the 21st Century, a large behavioral health organization is reviving, and in some ways, reinventing this innovative recovery approach. Crestwood Behavioral Health will present four innovative phases for their organizational and service transformation: 1) creating the vision for the "Big Bang" in optimum recovery outcomes; 2) implementing long-term sustainability and program evaluation process utilizing lessons learned; 3) preparing leadership and staff for organizational recovery; and 4) preparing and training peer support specialists. Peer support specialists can optimize recovery outcomes for a mental health organization and system.

Engaging and involving stakeholders to address organ transplant abuse in China

David Matas

dmatas@mts.net
International Coalition to End Transplant Abuse in China

Engaging and involving stakeholders to address organ transplant abuse in China has been difficult. The primary stakeholders are transplant doctors and nurses, hospitals, medical research publications, pharmaceutical companies, and manufacturers of organ preservation devices. Each of these has been involved fitfully and to a limited extent in addressing organ transplant abuse in China. Their efforts have been unsystematic and incommensurate with the gravity of the problem.
The paper would
• consider whether the engagement and involvement of stakeholders is necessary or important in addressing organ transplant abuse in China,
• set out the engagement and involvement by the various stakeholders to date,
• point to areas where stakeholders have been disengaged and uninvolved,
• attempt to identify the reasons for the disengagement and the lack of involvement, and
• suggest ways in which engagement and involvement could increase.
The conclusions would be
• engagement and involvement of stakeholders in addressing organ transplant abuse in China would be an important factor in ending the abuse, and
• there is a reasonable prospect, with the right measures, for more systematic and sustained engagement and involvement of stakeholders than there has been.

Challenging the 14-Day Rule of Embryo Research

Authors: Francis J. O'Keeffe, George L. Mendz
Presenter: George Mendz

George.Mendz@nd.edu.au
School of Medicine, The University of Notre Dame Australia, Sydney, Australia

Individuation has been regarded a necessary criterion for human embryos to be considered human beings and thus afford them appropriate status. It is argued that if an early human embryo can split into two or more distinct viable organisms it is not a single individual; hence, there is no foundation to treat embryos as human beings and to offer them protection until individuation is assured. Advocates for early human embryo experimentation propose that individuation is guaranteed when the twinning potential of a zygote or embryo ceases. Based on an accepted human embryo developmental model this situation has been timed at about 15 days post-fertilisation; thus, a 14-day limit within which embryo research may take place has been established in many jurisdictions. This study examines the model and the biological conclusions that arise from it, and discusses whether it is supported by data, aligns with contemporary biology knowledge, and explains instances of atypical twinning. The conclusion of the work is that the model is based upon speculative biology that does not account for many observations. It is a conceptually defective hypothesis and thus unsuited to serve as the basis for ethical determinations regarding human life and death.

Disruptive innovation in healthcare and respect for personal autonomy: a perfect match or a doomed couple?

Heidi Mertes

heidi.mertes@ugent.be
Ghent University, Belgium

A common theme and selling point for all kinds of disruptive innovation in healthcare, be it mHealth, eHealth, direct-to-consumer genetic testing or care robots, is that these new forms of healthcare create independency for the patient from third parties, thus empowering them and reinforcing personal autonomy. This line of reasoning has obvious intuitive appeal: parties that are traditionally in positions of power over the patient's health (health care professionals) and may occasionally be overreaching in exercising that power, are cut out of the loop or find their roles reduced. However, the idea that this vacuum is now filled with power for the patient has been criticized as misleading, as at least some of that power is diverted to the companies providing these new services to the patient and as new players on the 'market' of healthcare are gaining control over patients through access to health data. Moreover, one can question the specific concept of autonomy that is used. Autonomous decision making does not equal isolated decision making, but is best supported by input from relevant others. Second, the informational component of healthcare (which is usually what is covered in these disruptive innovations) is deficient in the sense that it does not incorporate the "care" component of health*care*.

This talk is part of the DIME panel discussion organized by Heidi Mertes.

Does pregnancy pose a risk to mental health?
An argument for permissibility of abortion

Dariusz Miękisz

dariusz.miekisz@student.uj.edu.pl
Doctoral School of Social Sciences, Jagiellonian University, Kraków, Poland

When in 2020 the Polish Constitutional Tribunal limited the right to abortion in cases of severe fetal malformations, a discussion began in the medical community whether many of the fetal abnormalities at the same endanger the pregnant woman's health (and so satisfy the requirement for abortion). In particular, the impact of abnormal pregnancy on woman's mental health has been raised.

In my talk, I argue that in the case of strict abortion law, even healthy pregnancy can be considered as posing a threat to woman's mental health. In the course of the argument, I analyze the notions of health, risk and causation. I distinguish three scenarios of how pregnancy can endanger woman's mental health: (1) as a biological fact, e.g. causing a postpartum depression; (2) as a psychological fact (3) in the dialectical situation of abortion legal ban. Large empirical studies confirm the real consequences of (3) scenario (Biggs et all., 2017).

Using expected utility analysis, I show that the value lost due to fetus' death is smaller than the value lost due to women's mental health deterioration. Using the pre-Rawlsian version of the veil of ignorance, I argue that a rational agent should opt for a liberal abortion law.

The Role of Psychiatry During the Holocaust: Perpetrators and Redemption

Susan Miller

smmiller@houstonmethodist.org
Houston Methodist Hospital, United States

Until the end of World War II, governmental institutions, private financiers, and wealthy patrons, funded what was then contemporary psychiatric research. Between 1918 and 1924, Paul Weindling describes the progressive development of eugenic thought and practice, which began to advance the concept of "euthanasia". Psychiatrists became instrumental in differentiating what medicine and society defined as normal versus abnormal. Moreover, psychiatrists helped enact laws which enforced psychiatric "therapies" as they also became the agents of these legislative mandates. Through their camouflage of social policies as medical science, and by broadening definition(s) of mental illness, they supported and expanded their burgeoning influence on the medical profession.

Psychiatrists gained "unprecedented power and status in the Nazi regime." Their disastrous tool for "preventing" mental illness and protecting the public's health was genocide. While psychiatrists stand out among medical professionals, the direct and systematic involvement of the entire medical community in the persecution, sterilization and mass murder of millions considered "unfit" was based on the very criteria medical personnel use to define those "unworthy of life." These behaviors represent the most egregious abuse of science and medicine in modern history.

Scientific research in higher medical education institutions through the prism of war: ethical dimension

Authors: Mykhailo Myroshnychenko[1], Viktoriya Lazurenko[1], Nataliia Kapustnyk[2], Nana Pasiyeshvili[2], Volodymyr Markovskyi[1], Maryna Mishyna[1]
Presenters: Mykhailo Myroshnychenko, Viktoriya Lazurenko

msmyroshnychenko@ukr.net, vv.lazurenko@knmu.edu.ua
[1] Kharkiv National Medical University, Kharkiv, Ukraine
[2] Public Nonprofit Organization of the Kharkiv District Council «Regional Clinical Perinatal Centre», Kharkiv, Ukraine

Introduction. The war in Ukraine drastically affected scientific research in higher medical education institutions.
The purpose was to highlight the ethical features of scientific research in higher medical education institutions in the conditions of war.
Results. The psychological state of researchers (constant shelling, loss of relatives, change of residence, etc.), their insufficient communication with the scientific supervisor, lack of experience and reduced motivation, domestic problems, lack of access to the laboratory contribute, unfortunately, to non-compliance with certain principles of academic integrity (plagiarism, fabrication, falsification, deception, etc.); violation of publishing ethics when they send the same materials to different journals at the same time.
Hospitals destruction causes non-compliance with the planned research design and the impossibility of long-term follow-up of patients. Medical duty is at the forefront in scientists who simultaneously conduct research and provide medical care to patients. The chronic stress state in research participants (people, experimental animals) as a reaction-response to the war actualizes the question of the „purity" of the conducted research.
Conclusion. Our analysis proved that the war in Ukraine makes it difficult to conduct scientific research in full compliance with ethical requirements.

Moral conflicts in familial dementia care involving migrant live-in carers in Germany and Israel: A comparative-ethical exploration and analysis

Authors: Anna-Eva Nebowsky, Dr. Milena von Kutzleben, Mark Schweda, Merle Weßel
Presenter: Anna-Eva Nebowsky

anna.eva.nebowsky@uol.de
Carl von Ossietzky University Oldenburg, Germany

The worldwide increasing demand for care capacities for people with dementia cannot be sufficiently met by professional caregivers or provided by family caregivers alone. So-called live-in care arrangements are intended to fill this care gap in countries all over the world. They refer to care arrangements in which the family caregiver is supported by a so-called '24-hour' migrant care worker. In addition to general social and legal problems, these arrangements lead to challenges in the immediate home environment that manifest themselves as *(moral) conflicts* in the persons themselves, between the live-in carer and the person with dementia and the family caregiver. In our study we investigate moral conflicts in live-in care arrangements in Germany and Israel. Israel has created binding legal regulations whereas in Germany a legal framework is absent. Our findings from ethnographic interviews with all members of these arrangements as well as stakeholders from the field (e.g. from placement agencies or politics) point to differing qualities in the arrangements depending on the country. They not only demonstrate an influence of the macro- and meso-structures on the micro-setting in general, but also reveal the impact on the people's life and the quality of the relationship between the involved persons.

Filial duties and advanced parental age:
Offspring's sense of responsibility towards their ageing parent(s)

Authors: Natalie Bettina Neeser, Tenzin Wangmo, Andrea Martani
Presenter: Natalie Bettina Neeser

nathalie.neeser@unibas.ch
Institute for Biomedical Ethics, University of Basel, Switzerland

The numbers of parents of advanced parental age (APA, here defined as 40+) is rising and much research is done on the risks for parents (esp. mothers) and children around birth, but little is known about how children of APA parents are doing when they become adults themselves. To find out more about their experiences in the context of Switzerland, an explorative semi-structured interview study was conducted with a total of 20 participants. Participants were aged between 18 and 37 years and at least one of their parents was 40+ years at the time of their birth. After thematic analysis, results show that children of APA parents are faced with decision-making processed and responsibilities towards their parent's care earlier in life in comparison with their peers. The family structure (e.g. the offspring's age, the family's size), time management issues (e.g. the degree of intensity of caregiving tasks required, time intensity in children's career), children's experiences growing up and geographic circumstances (e.g. living far or nearby) influence how offspring perceive their filial caregiving duties towards their parents. By considering these findings, we reflect on the expectations and filial duties in terms of caregiving of adult children towards their APA parents.

The request of physician assisted suicide in palliative care: the role of the clinical ethics consultation

Authors: Federico Nicoli, Mario Picozzi
Presenter: Federico Nicoli

federico.nicoli82@gmail.com
Center for Clinical Ethics, Department of Biotechnologies and Life Sciences,
University of Insubria, Varese, Italy

The aim of this paper is to offer an analysis of the literature and a theoretical and practical reflection related to the request by a patient for physician-assisted suicide in palliative care.

Choosing to want to end one's life while being "reassured" about the procedure by the health care setting where it might take place involves ethical dilemmas not only for the patient and their family members, but also for the palliative care professionals over the course of care.

A situation is created in which the patient might seem to play a primary role (because the last word and the last gesture are up to the patient); on the other hand, the healthcare professionals might end up playing a primarily technical role, which seems to conflict with the fundamental meaning of the "act of care".

Clinical ethics consultation seems to offer an opportunity to face these ethical dilemmas before the final choice is made. Some questions that will be attempted to be answered here are: is it ethically permissible to offer help in taking one's own life in a palliative care setting? Should one attempt to change another person's mind? When and with whom must the choice be shared?

Relational care ethics as alternative approach for respectful maternity care

Inge van Nistelrooij

i.vannistelrooij@uvh.nl
Radboud University, Nijmegen & University of Humanistic Studies, Utrecht,
The Netherlands

In health care and ethics attention for pregnancy and birth is often focused upon the child. Less attention is paid to the pregnant and birthing person's perspective. Since this is often to the detriment of birthing persons, the global movement against 'obstetric violence' (OV) has gained traction globally. The term emerged in the early 2000s in Latin and South-America, spreading throughout the Global South and travelled into Europe, where obstetric observatories have been founded in France and Spain (Chadwick 2021). As ethicists we draw attention to the ethical approach of obstetrics, in which an individualistic approach dominates and results in a separation of the interests of baby and birthing person, and the subsequent undervaluation of the latter's interests. We argue that care ethics offers an alternative approach that emphasizes relationality, counterbalances harmful individualism, provides philosophical insights into pregnancy, and supports respectful maternity care. Our research (Van der Waal & Van Nistelrooij, 2022) sheds more light on the ethical and existential questions concerning the birthing person in a time when international political and medical developments put pressure upon the position of pregnant and birthing persons.

Inappropriate Adaptive Preferences in Artificial Intelligence: a Qualitative Study of the Role of the Patient

Laura Arbelaez Ossa

laura.arbelaezossa@unibas.ch
Institute of Biomedical Ethics, University of Basel, Switzerland

Background. There is significant enthusiasm about Artificial Intelligence (AI) potentials but also concerns about using AI in a manner acceptable for patients. This study explores how patients and expert stakeholders envision patients' role in AI usage for healthcare.

Methods. We conducted semi-structured interviews with 20 patients and 20 experts in Switzerland and Germany. We analyzed the data using reflective thematic analysis.

Results. We developed three themes: (1) 'resignation to passivity', which depicts how patients fear AI and their lack of control; (2) 'limitations as beliefs systems', which describes how patients and experts believe patients have limited capacities to handle AI; (3) 'desires to hand-over AI interactions', explains how patients see acceptable to defer their decisions to experts.

Discussion. The findings suggest that patients have internalized limitations about their capacities, while experts seem to believe paternalistic approaches are acceptable in AI due to patients' perceived limitations. This consensus may be explained by adaptive preference formations, where patients and experts have modified their preferences, based on common AI narratives of complexity and unavoidability. To promote active patients' participation in AI in healthcare, these beliefs and narratives would have to be re-adapted.

Converging new technologies:
on the person, for the common good

Rev. Renzo Pegoraro

cancelliere@pav.va
Pontifical Academy for Life, Vatican City; Fondazione Lanza, Padua, Italy

Since 2001, in the United States started to talk about converging technologies, meaning emerging technologies that are rapidly developing, pervading different realities (biological, human, social), and that tend to integrate, i.e. 'converge' towards common goals. These are: Nanotechnology, Biotechnology, Computer Science and Artificial Intelligence, Cognitive Science, collectively referred to as NBIC.

The European Union, in 2004, added the Social Sciences to the aforementioned technologies, and the acronym became CTEKS, or 'Converging technologies for the European Knowledge Society'.

There is the proposal for a 'human-centred' vision, i.e. one that places the human person at the centre, recognising his/her intrinsic dignity and freedom. It is urgent to define the possibilities and limits of these technologies, appreciating their benefits, especially in the health field, but also considering the risks, the effects on the most vulnerable, poor, conditioned people. There are also issues of justice, solidarity, sustainability, transparency, and the real availability of the applications of these technologies (see the issue of patents). There is therefore a need for a trans-disciplinary approach, for a deeper and more constructive dialogue between scientists, philosophers, theologians, and other experts in the humanistic and socio-economic fields, promoting the elaboration of ethical criteria and rules for the 'governance'.

Public perceptions and expectations of organoid research

Mario Picozzi

mario.picozzi@uninsubria.it
Center for Clinical Ethics, Biotechnology and Life Sciences Department, Insubria University, Varese, Italy

Organoid technologies are rapidly advancing and hold great potential and hope for disease modelling and clinical translational research. Still, they raise a number of complex, ethical questions regarding their current and future use. In that field, patient and public involvement could be helpful in building public trust and helping to secure responsible conduct and valued innovations; however, there is little data on how patients and the general public feel about organoid technologies. The contribution aim at report the results of a first public dialogue on organoid technologies through three cross-country deliberative workshops with a diverse group of stakeholders to identify their perceptions and concerns. Most participants support organoid technologies on the condition that they are governed ethically, have proper oversight, and respect informed consent practices. They also identified a broad set of potential concerns, primarily concerning commercialization, healthcare access, and cerebral organoids. Participants' insights and recommendations can help inform researchers and ethics and policy bodies toward supporting responsible and ethical organoid approaches.

When cancer therapy threatens fertility – The importance of time and concepts of good life in cancer and treatments that threaten fertility

Ines Pietschmann

ines.pietschmann@med.uni-goettingen.de
Department of Medical Ethics and History of Medicine, University Medical Center, Göttingen, Germany

We have different conceptions of what makes our life a good life. The question of having children is often an essential point in shaping a good life. But not only whether children shall be part of it, but also when they shall become part of it, is something many people negotiate with themselves or with others at some point in their lives.

Cancer can dramatically affect and even challenge these concepts of a good life. Some cancers and especially cancer treatments interfere with the possibility of having biological children or even make it impossible. Therefore, many patients have to think about fertility issues and possible fertility preservation within a very short time frame. Decisions in such a challenging situation have various ethical dimensions as well as various medical factors.

This lecture aims to show the complexity of the decisions that patients are confronted with. The influence of personal and social concepts of a good life on the decision will be discussed. What role do current, or future partners play? What influence does time have on these decisions? Finally, an outlook is given on the consequences of these questions for good patient information and guidance.

Is the revision of the dominant classifications of aid-in-dying procedures necessary?

Maciej Ferdynand Piwowarski

m.piwowarski@doctoral.uj.edu.pl
Doctoral School in the Humanities and Interdisciplinary Centre for Ethics,
Jagiellonian University, Kraków, Poland

In my talk, I want to shed some light on the root causes of the discrepancies in regulating aid-in-dying (AID) in different countries. I claim that they can be attributed to different ways in which axiological, or more broadly philosophical, presuppositions are embedded in the normative regulations and decisions regarding AID: we can find different approaches to understanding the difference between *killing* and *letting die* (or more broadly *act* and *omission*), the moral significance of intention, understanding causality, valuing "a natural" course of events, patient autonomy, as well as medical paternalism.

Moreover, I would like to propose a somewhat unorthodox conceptual framework for classification of various AID procedures. In my view, they include: active voluntary euthanasia, assisted suicide and – what is more controversial – palliative sedation, lethal analgesia, as well as even withholding or withdrawing life-saving or life-prolonging medical treatment. I claim that those procedures are a part of a single spectrum, and the differences between them are mostly practical, but hold no moral significance in themselves. What distinguishes the practices that are morally acceptable from those that are not is whether they are conducted according to the fully informed patient's autonomous wishes.

Keeping an AI on the mental health of vulnerable populations: Reflections on the Potential for Participatory Injustice

Authors: Michiel De Proost[1], Giorgia Pozzi[2]
Presenter: Michiel De Proost

michiel.deproost@ugent.be

[1] Bioethics Institute Ghent, Department of Philosophy and Moral Sciences,
Ghent University, Belgium
[2] Faculty of Technology, Policy and Management, Delft University of Technology,
The Netherlands

Considering the overall shortage of therapists to meet the psychological needs of vulnerable populations, AI-based technologies are often seen as a possible remedy. Particularly smartphone apps or chatbots are increasingly used to offer mental health support, mostly through cognitive behavioural therapy. The assumption underlying the deployment of these systems is their ability to make mental health support accessible to generally underserved populations. Hence, this seems to be aligned with the fundamental biomedical principle of justice understood in its *distributive* meaning. However, considerations of the principle of justice in its *epistemic* significance are still in their infancy in the debates revolving around the ethical issues connected to the use of mental health chatbots. This paper aims to fill this research gap, focusing on a less familiar kind of harm that these systems can cause, namely the harm to users in their capacities as knowing subjects. More specifically, we frame our discussion in terms of one form of epistemic injustice that such practices are especially prone to bring about, i.e., *participatory injustice*. To make our theoretical analysis more graspable and to show its urgency, we discuss the case of a mental health Chatbot, Karim, deployed to deliver mental health support to Syrian refugees. This case substantiates our theoretical considerations and the epistemo-ethical concerns arising from the use of mental health applications among vulnerable populations. Finally, we argue that these systems should be designed for epistemic justice in order to enhance, rather than constrain, users' epistemic participation.

Elements of social polarisation and their implications in clinical practice ethics in Romania

Authors: Mária Rajka[1,2], Maria Aluaş[2]
Presenter: Mária Rajka

rajkamaria@yahoo.com

[1] Dr. Cornel Igna Municipal Hospital of Campia Turzii, Romania
[2] Iuliu Hatieganu University of Medicine and Pharmacy, Cluj Napoca, Romania

Introduction. When speaking of polarisation, we think at two group of people with opposite opinion. Also, we can refer at two different groups of the society, divided by differences of race, culture, poverty, or their health status. We aim by this presentation that the polarisation of the society will influence the health status of their individuals. The wealthy will be healthy, and the poor will be unhealthy.

Context. We will focus on the subject by studying the elements of patient's compliance at medical treatment in Romanian healthcare settings, by interviewing healthcare professionals.

Discussions. The social determinants of health predefine the health status of the individuals, that can lead to social injustice. The bioethical elements of this theme are the question of equity, health education, patients understanding, adherence to treatment.

Conclusions. Giving a patient a good medical treatment is not enough for him or her to be healthy, all the other questions will start after the consultation. Will the patient purchase the medicine? Did he or she understand the diet that is necessary? All these elements will majorly influence the health status of the citizens, but only by realizing it can we improve them.

What do bioethicists believe? The results of a survey to researchers in bioethics, medical ethics and philosophy of medicine

Authors: Joona Räsänen, Niina-Maria Nissinen, Pekka Louhiala
Presenter: Joona Räsänen

joona.rasanen@ps.au.dk
University of Turku, Finland

What are the ethical views of researchers working in bioethicists and closely related fields? Is abortion morally permissible? Is commercial gamete donation ethically permissible? Should patients be allowed to refuse treatment that would be beneficial for them? At what age can a child refuse medical treatment to which her parents have consented? Is it ethical to use animals in biomedical research? Is there a moral obligation to be vaccinated? These are some of the 60 questions we asked of professional bioethicists. We divided the questions into seven themes, framed questions as statements and asked scholars to respond whether – and to what extent – they agree with the statements. The seven themes were: reproductive ethics, treating of patients, research ethics, human enhancement, public policy, sexuality and gender, and death and dying. We analyzed the responses received from a total of 200 researchers and documented the results. The analysis shows correlations among ethical views and between the ethical views and factors such as career stage, gender, the field of one's PhD, and religious belief. We present the results of the survey.

Health as a duty

Authors: Francesca Reato, Emanuele Mangione, Gioacchino Costa
Presenter: Francesca Reato

francesca.reato1974@gmail.com
Center of Research in Clinical Ethics, University of Insubria, Varese, Italy

Among the values enshrined in the WHO Constitution, the enjoyment of the best attainable state of health is referred to as a fundamental right. This corresponds to an ethical dimension of health, which translates into the need for health education for citizens. Health as a collective good could also be interpreted as a duty, which is here understood as a necessary counterpart to right.

2023 has been proclaimed "European Year of Competences". The need to invest more in the development of competences calls for reflection on the responsible management of personal and social health.

Transversal actions of empowerment, which encourage the autonomy of people and the assumption of responsibility for the care of their health, are also recalled in the European political model "Health 2020".

To make people active protagonists of healthy and conscious choices, a new path of collective health education is necessary, that involves health professionals and value the concept of health, both as a right and a duty.

The portfolio of 8 key European competences for lifelong learning should include a competence dedicated to specific knowledge and skills, and take into account health literacy, to be already strengthened in compulsory education schools.

Donor anonymity and justice

Authors: Caroline AB Redhead, Lucy Frith
Presenter: Caroline AB Redhead

caroline.redhead@manchester.ac.uk
Centre for Social Ethics and Policy, School of Law, The University of Manchester,
United Kingdom

In this paper, we consider gamete donor anonymity, as both a principle and the legally protected status of a donor, from the perspective of donor-conceived people who, having no legal route to access information about their genetic origins, have to turn to online DNA testing. The discussion is framed by an interpretation of reproductive justice as an interdisciplinary theory and practice that pays attention to non-biological issues affecting reproduction and parenting experiences in relation to the state and other authorities. Our interest here is the issue of donor anonymity. We explore how the conflicts between online DNA testing, laws protecting donor anonymity and the interests of donor-conceived people harm and constrain the options of donors, donor-conceived people, and their families. Questioning the legal and ethical issues implicated in the right to be(come) a parent by donor conception under conditions of anonymity, we draw out issues of reproductive (in)justice at the intersection of assisted reproduction, digital health data and the construction of (family) identity. We draw on semi-structured interviews and focus group discussions with donors, donor-conceived people, parents through donor conception and regulators in the field to further develop the analysis.

A principle-based framework for ethical research payment

Joanna Różyńska

j.rozynska@uw.edu.pl
Center for Bioethics and Biolaw, Faculty of Philosophy, University of Warsaw, Poland

While most publications on the ethics of paying research subjects start by identifying major ethical concerns raised by the practice (in particular, risks of undue inducement and exploitation), and end with a set of – more or less well justified – ethical recommendations for using payment schemes immune to these problems, this presentation takes a top-down approach and offers a systematic, principle-based ethical analysis of the practice. It argues that researchers have a prima facie moral obligation to offer payment to research subjects, which stems from the principle of social beneficence. This principle constitutes an ethical "spine" of the practice. Other ethical principles of research ethics (respect for autonomy, individual beneficence, and justice/fairness) make up an ethical "skeleton" of morally sound payment schemes by providing additional moral reasons for offering participants (1) recompense for reasonable expenses; and (2a) remuneration conceptualized as a reward for their valuable contribution, provided (i) it meets standards of equality, adequacy and non-exploitation, and (ii) it is not overly attractive (i.e., it does not constitute undue inducement for participation or retention, and does not encourage deceptive behaviors); or (2b) remuneration conceptualized as a market-driven price, provided (i) it is necessary and designed to help the study achieve its social and scientific goals, (ii) it does not reinforce wider social injustices and inequalities; (iii) it meets the requirement of non-exploitation; and (iv) it is not overly attractive. The principle of justice provides a strong ethical reason for not offering recompenses for lost wages (or loss of other reasonably expected profits).

Emerging Technologies and Vulnerabilities in Older Adults with Cognitive Impairments: a Systematic Review of Qualitative Evidence

Authors: Virginia Sanchini[1,2], Annachiara Fasoli[1], Chris Gastmans[2]
Presenter: Virginia Sanchini

virginia.sanchini@unimi.it

[1] Department of Oncology and Hemato-Oncology, University of Milan, Milan, Italy
[2] Centre for Biomedical Ethics and Law, Department of Public Health and Primary Care, KU Leuven, Leuven, Belgium

Background. Recently, a great emphasis has been placed on Emerging Technologies (ETs) designed for the elderly. A vast amount of both theoretical and empirical literature has appeared, exploring the ethical implications of ETs in the context of daily management and care of (frail) older adults. However, to the best of our knowledge, no comprehensive research has been carried out over the impact of ETs on older adults' vulnerability, focusing, in particular, on elderly people with cognitive impairments, who are the main beneficiaries of ETs.

Methods. Using the PRISMA procedure, we conducted a systematic review of empirical (qualitative) evidence. Five major databases (Pubmed, Embase, Web of Science, CINAHL and Philosopher's Index) were queried and, eventually, 52 articles were critically analysed, following the QUAGOL methodology.

Results. ETs seem to act in a twofold manner: they tame some already existing vulnerabilities, and, at the same time, they worsen already existing or create new vulnerabilities. For instance, some unconventional monitoring techniques (e.g. wearables) tame "physical vulnerability", by providing sense of safety and constant monitoring, but threat "psychological vulnerability", causing frustration related to inherent technology's limitations and to a lack of familiarity with the technology.

The best preparation for ethical conflicts during the pandemic: watching movies!

Kurt Schmidt

Kurt.Schmidt@ekhn.de
Center for Medical Ethics, Agaplesion Markus Hospital, Frankfurt/M, Germany

Those best prepared for the pandemic were movie-goers and avid series watchers, or at least they were already familiar with the ethical problems involved. Long before the COVID-19 pandemic, movies and TV series had been addressing explosive questions which now suddenly had to be answered in real life: When resources – like vaccines or hospital beds – are short, who should be treated first? What right or obligation does the state have to restrict civil liberties in order to protect the lives and health of its citizens?

A short history of film, from 1970s disaster movies to 2020s pandemic thrillers, will demonstrate how ethical conflicts are solved in movies and which changes in ethical argumentation have come about as a result. Movies such as the quasi-documentary thrillers OUTBREAK (1995) and CONTAGION (2011), or more subtly BLINDNESS (2008), or countless zombie films or hospital series, are now available all over the world. But the solutions they provide are not always compatible with country-specific ethical and constitutional principles. The interesting aspect of how decision errors impact in catastrophic situations will also be shown.

Shedding Light on Blind Spots in Clinical Ethics:
Towards a New Horizon

Authors: Marie-Christine Fritzsche[1], Anna-Henrikje Seidlein[2],
Rouven Porz[3], Helen Kohlen[4]
Presenters: Marie-Christine Fritzsche, Anna-Henrikje Seidlein

anna-henrikje.seidlein@med.uni-greifswald.de

[1] Institute of History and Ethics of Medicine, TUM School of Medicine,
Technical University of Munich, Germany
[2] Institute of Ethics and History of Medicine, University Medicine Greifswald, Germany
[3] Insel Gruppe Bern, Bern, Switzerland
[4] Vincenz Pallotti University, Vallendar, Germany

Clinical Ethics has become an established field in many Western hospitals and healthcare institutions. While there is extensive knowledge and procedures on how to work in Clinical Ethics, in particular how to properly conduct Clinical Ethics Consultation, we perceive some epistemological gaps in these approaches. This becomes paradigmatically clear when ethical decision-making is usually reduced to the four bioethical principles. We believe that this creates epistemic blind spots, e.g. with regard to power structures, relations, context and vulnerability. We are convinced that integrating these aspects can broaden the scope of ethical case discussions.

In this presentation, we build on our proposal for the EACME Collaboration Award 2022 and present results of our ongoing work since then. We show how incorporating feminist theories can provide a more nuanced and comprehensive understanding of the ethical issues at play, ultimately leading to more equitable decision-making.

We call for a systematic examination of feminist ethical concepts in Clinical Ethics Consultation and their integration into existing models based on theoretical research, quantitative and qualitative studies.

Bioethics across the border- the ethical implications of the patients mobility between Germany and Poland

Anna Sierawska

anna.sierawska@tu-dresden.de
TU Dresden University of Technology, Technical University of Munich, Germany

Despite the physical proximity between Poland and Germany, there are differences between the two countries in terms of language, customs, healthcare systems, legal frameworks, and socioeconomic conditions. These differences and the membership of both countries in the European Union make cross-border healthcare a complex bioethical field. OECD, EU and various regional organizations collect data on patients' mobility. This mostly quantitative data serves for statistical analyses or assessment of patients' experiences. Some of attention has been paid to ethical issues as medical tourism, e.g., in areas of reproductive health or shortages in healthcare staff. There is lack, however, of systematic mapping of the ethical issues that arise in the healthcare provision and patients' mobility between Poland and Germany.

This paper examines the key areas of healthcare provision that are influenced by the political and geographical circumstances between Poland and Germany. Through a series of examples, we identify and highlight the ethical and social issues that arise in the delivery of cross-border healthcare. Our goal is to highlight successful models, identify areas in need of improvement, and provide a foundation for further research. Ultimately, we aim to promote a more refined and ethically informed approach to healthcare delivery between Poland and Germany.

The PHERCC matrix. An ethical framework for planning, governing, and evaluating Risk and Crisis Communication in the context of Public Health Emergencies

Giovanni Spitale

giovanni.spitale@ibme.uzh.ch
Institute of Biomedical Ethics and History of Medicine, University of Zurich, Switzerland

Risk and crisis communication (RCC) is a current ethical issue subject to controversy, mainly due to the tension between individual liberty (a core component of fairness) and effectiveness. In this presentation, based on a paper recently accepted by the American Journal of Bioethics, we propose a consistent definition of the RCC process in public health emergencies (PHERCC), which comprises six key elements: evidence, initiator, channel, publics, message, and feedback. Based on these elements and on a detailed analysis of their role in PHERCC, we present an ethical framework to help design, govern and evaluate PHERCC strategies. The framework aims to facilitate RCC, incorporating effectiveness, autonomy, and fairness. It comprises five operational ethical principles: openness, transparency, inclusivity, understandability, and privacy. The resulting matrix helps understanding the interplay between the PHERCC process and the principles of the framework. The presentation includes suggestions and recommendations for the implementation of the PHERCC matrix in real-life scenarios.

From „exceptional ethics" to public health ethics.
Patients and proxies facing COVID

Marta Spranzi

marta.spranzi-ext@aphp.fr
Center for Clinical Ethics, AP-HP, Paris, France; CESP Paris Saclay, France

Objectives. The study aimed at eliciting the perception and ethical considerations of patients and proxies with respect both to the individual medical decisions and public health decisions made during the COVID crisis.

Methodology. A qualitative multi-centric study based on semi-directive interviews, conducted by an interdisciplinary team. The analysis was conducted using a thematic analysis approach and an ethical grid.

Results. Three themes emerged from the analysis: 1) patients, unlike proxies, did not complain about their diminished role in the decision-making process. Both highlighted the importance of "basic care" as opposed to a technical approach to treatment; 2) despite the transparency of the information process, a deep "crisis of trust" has developed between citizens and public authorities; 3) although both patients and proxies accepted the limitations of personal liberties imposed in the name of public health, they argued that these limitations should respect certain boundaries both temporal and spacial. Above all, they should not affect basic affective human relationships, even if such boundaries affect an increased risk of infection.

Conclusion. The study shows that there is a need for reconsidering the definition and the main principles of public health ethics: transparency and proportionality.

Planning disruption? An empirically informed ethical analysis of moral conceptions of the life course in advance directives

Lena Stange

lena.stange@uni-oldenburg.de
Division Ethics in Medicine, Department of Health Services Research,
School of Humanities and Social Sciences, Carl von Ossietzky University of Oldenburg,
Germany

Advance directives (AD) count as an expression of the authors' self-determined will regarding their medical treatment in later life. So far, the ethical discourse has primarily been concerned with their formal structure and legal validity. However, the ethical questions involved require a broader examination of individual conceptions of the good life and of ways of dealing with possible disruptive experiences that are neither imaginable nor plannable. To explore such conceptions, qualitative interviews comprising questions about life plans and ideas regarding health and aging were conducted with 18 individuals in four age groups. Their perspectives were analysed through the lens of an ethics of the good life and contextualised with considerations regarding AD. The results show that people are often not aware of their fundamental values and their practical implications for AD. The identification of these implications is important regarding individual orientations and motivations regarding later life. Furthermore, striving for self-determination does not automatically lead to the awareness of the scope of an AD. The consideration of moral conceptions of the life course is relevant for medical ethics and policy as they might have far-reaching consequences for individual health care. This broadens the discourse about the impact and limitations of AD.

Making Advance Directives (AD) during a pandemic – a curse or a blessing?

Elisabeth Stock

elisabeth.stock@unibas.ch
Institute for Biomedical Ethics, University of Basel, Switzerland

Since the outbreak of the COVID-19 pandemic, healthcare systems have been facing many challenges, especially in how to deal with scarce medical resources. Guidelines were drafted to ensure ethically sound rationing of critical resources. At the same time, there was a call to patients to fill in Advance Directives (AD) regarding treatment preferences in critical care situations, so that interventions would be limited only to those who explicitly desire them. Hence, AD could be a viable solution to help distribute limited resources more efficiently. Conversely, ethical concerns related to encouraging persons to fill in AD have been highly discussed (e.g. because of the difficulty to decide about future scenarios, as preferences can change over time and a scenario like the Covid-19 pandemic was completely new with limited information/experiences available to the public). In this presentation, I will use a normative approach to discuss whether it is ethically desirable to promote AD implementation during times of resource scarcity as a tool to allocate resources and focus on additional values of AD, such as avoiding futile treatment and encouraging a discussion about the topic of death and dying in the medical context.

Inclusive bioethics: modifying methodology to transform research

Authors: Kumeri Bandara[1,3], Matimba Swana[2,3], Harleen Kaur Johal[2,3]
Presenter: Matimba Swana

matimba.swana@bristol.ac.uk

[1] University of Oxford, United Kingdom
[2] University of Bristol, United Kingdom
[3] Black and Brown in Bioethics, United Kingdom

In this paper, we map out kinds of discrimination and bias inherent in mainstream research methods, and call for critical engagement with and rethinking of these methods. The paper is based on our experiences as researchers from minoritised backgrounds; reflections on planning, developing, and executing empirical research projects as part of our respective PhDs; and involvement in other research projects. We draw from a collective data set of 100 interviews we carried out in the UK in 2022 and 2023 for our PhDs, corollary research experiences, and associated methods. We outline the structural and individual biases inherent in developing research questions, recruiting participants, selecting consent processes, advertising projects, interviewing, and coding data, among other methodological steps. We contextualise our discussion within existing critiques that appear in decolonial and feminist literature to show how the unconsidered use of methods in bioethics research can exclude and undermine minoritised and underprivileged communities' experiences and voices. We also show how such exclusion deprives bioethics research of data that is truly representative of the diverse communities around us. Finally, we emphasise the need for more focused research on discrimination and biases in mainstream research methods and discuss how we might overcome these issues.

Ethical Issues Surrounding the Care of ALS-FTD:
How to Respond to Insatiable Demands

Jun Tokunaga

tokunagajun@gmail.com
Sayama Neurological Hospital, Japan

Amyotrophic lateral sclerosis (ALS), a slowly progressive loss of muscle strength throughout the body, can be associated with frontotemporal dementia (FTD), which is characterized by deinhibition, lack of empathy and empathy, and compulsive behaviors. When these symptoms appear in the advanced stage of ALS, care providers are unable to meet the patient's insatiable demand for care, and ethical issues arise. We conducted a descriptive study of patients with tracheostomies and ventilators by surveying care providers. In cases where nurse calls reached more than 800 times per day, the nurse call was eventually removed with consent. The care providers appreciated the fact that they were able to free the patients from compulsive behaviors. In contrast, in another case, the caregiver turned off the nurse call without informing the patient when the patient was no longer able to ring the nurse call due to the advanced stage of the disease, a response to anxiety that was considered supportive. Ethical issues related to ALS-FTD should be explored in a manner that is appropriate to the individual patient's situation, rather than being limited by principles.

Ethical aspects of conducting research: point of view of medical university students

Authors: Kateryna Topoliuk, Maryna Tsymbal, Mykhailo Myroshnychenko
Presenter: Kateryna Topoliuk

p.catherinetop@gmail.com
I Medical Faculty of Kharkiv National Medical University, Ukraine

Introduction. The problem of ethical requirements compliance during conducting research is extremely urgent. The students of medical university as future scientists should have excellent knowledge about the moral standards of behavior during conducting research.

The purpose was to assess the awareness of student researchers of medical university regarding the ethical component of research.

Materials and methods. It was conducted an online survey of 110 students of Kharkiv National Medical University (Ukraine), who are actively involved in research even during the war in Ukraine.

Results. 75.5% of respondents were familiar with the concept of „ethics of research", 18.2% of respondents found it difficult to answer, and 6.3% answered unequivocally that they were not familiar. 87% of respondents believed that the observance of the principles of ethics during conducting clinical or experimental research is important or extremely important, and 13% of respondents considered them not mandatory. 81.2% of respondents always and often adhered to ethical principles, and 18.8% – rarely or did not comply.

Conclusions. The study conducted by the authors indicates the need to improve students' knowledge of ethical norms and rules during performing clinical and experimental researches.

„Free HPV Vaccination after 18?":
A Qualitative Study on Awareness of University Students about HPV Infection and Vaccination Policy in Turkey

Authors: Yesim Isil Ulman[1], Gülşah Başkavak [2]
Presenter: Yesim Isil Ulman

yesimul@yahoo.com

[1] History of Medicine & Ethics Department, Acibadem University School of Medicine, Istanbul, Turkey
[2] Sociology Department Acibadem University Faculty of Humanities, Istanbul, Turkey

Human papillomavirus (HPV) is one of the viruses found in humans, and has many species. HPV infection can cause genital warts or some types of cancer in humans, such as cervical, anus, penis, vulva, vagina, and head and neck cancer.

HPV vaccine has been a heated debate in Turkey recently. Citizens and associations have conducted a free HPV vaccination campaign for everyone for two years. As a result of these efforts, the Ministry of Health announced that the HPV vaccine would be included in the national vaccination calendar in consideration with the marital status and over the age of 18 in December 2022. However, WHO recommends that vaccination can be started girls aged 9-14 years before starting sexual activity. This has caused a bioethical, socio-political conflict in the issue. Thus, this declaration of Ministry has aroused a public debate targeting an amendment in the draft policy.

This qualitative study aims to investigate the awareness, opinion, experiences, prevention methods of students of Acýbadem University in Istanbul regarding the HPV. By conducting this study, we intend to contribute the relevant literature to better serve health policies and health coverage from an evidence- based perspective in line with accountability, equity, and social responsibility.

Movement fragmentation:
opening new neuroethical perspectives

Marta Vassallo

mvassallo2@uninsubria.it
University of Insubria, Varese, Italy; IRCCS Maugeri, Department of Neurology, Milan, Italy

Movement is one of the defining functions of the human body, for this reason it is essentially linked to our nervous system and our brain's functionality.

In today's landscape where gaining an understanding of our brains is essential, assessing the neurological component of movement is one way to externally understand and evaluate human brains. Then, fragmenting movement is necessary for two main reasons:

Obtaining a cognitive map of movement

Improving rehab techniques

Fragmenting movement considers various aspects of the same concept: this can be accomplished via the deconstruction of the motor act. The first step to assess movement in humans is to consider genetic variation that is specific to our specie. Also, we need to consider both top-down elements such as motion, perception and intention, and bottom-down elements such as muscles and joints, and more broadly the entire musculoskeletal system. Our proposal has several levels to it, but here we highlight the neuroethical and bioethical levels, that are intertwined with healthcare and rehabilitation for neurological diseases involving movement.

Therefore, we maintain that focusing on movement on a neuroethical perspective could provide an impactful change in healthcare and in the way we manage, treat and care for disabilities.

The Ethics of Doing Research through Consumer Mental Health Apps: Interviews with Researchers and Developers

Authors: Kamiel Verbeke, Charu Jain, Ambra Shpendi, Pascal Borry
Presenter: Kamiel Verbeke

Kamiel.verbeke@kuleuven.be
Center for Biomedical Ethics and Law, Faculty of Medicine, University of Leuven, Belgium

Mental health and wellness consumer apps are booming, with about 10.000 to 20.000 currently available on app stores. This is accompanied by an increased interest to generate generalizable knowledge about health from these tools (e.g., does the app work?), whether done within the traditional scientific enterprise or less traditional contexts such as corporate research and development. In this study, we focus on apps that are not primarily developed for the purpose of doing academic research, but which are still leveraged for deriving knowledge from the health-related data of actual app users. While advocates for these apps may use such knowledge to highlight their potential, others warn for sometimes significant risks. They argue that such risks may emanate from ineffective ethical deliberation, oversight and regulation. However, little work has addressed the ethics of generating generalizable health knowledge through mental health apps, although researchers and app developers will nevertheless be confronted with it. Therefore, we have interviewed 17 researchers and developers about topics such as risks and benefits, ethical safeguards, oversight and regulation, and facilitators and barriers to ethical decision-making. Through our study, we aim to contribute to the understanding and best practices for generating generalizable health knowledge through mental health apps.

Gerontechnology and deception in dementia

Rasita Vinay

rasita.vinay@ibme.uzh.ch
Institute of Biomedical Ethics and History of Medicine, University of Zurich, Switzerland

The utilisation of digital technologies in healthcare for elderly patients – or gerontechnology – has been more widely received since the COVID-19 pandemic. There are many examples of gerontechnologies which have provided social, educational or psychological assistance with feeding (i.e., Secom's MySpoon), hair washing (i.e., Panasonic's Hair-Washing Robot), mobility (i.e., LEA the robotic walker), or even as a replacement to pet therapy (i.e., PARO the seal). Their functionality has been heralded by their ability to promote aging in place, to reduce carer-burden, and even improve standards of living, especially for those living with cognitive impairments such as dementia. However, this also raises questions on their truth-bearing agency, and the risks of infantilisation and anthropomorphisation. This paper provides a bioethical discussion on the atribution of human traits to non-human entities, which are employed to interact and create a sense of familiarity, trust and enhanced companionship for people living with dementia. The role of deception is then further explored in comparison with other (non-technological) common practices in dementia care, such as simulated environments in the form of fake bus stops, train stations and dementia villages.

Obligation to Write Advanced Directives: Blackmail or Care of a State?

Olga Vinogradova

olga.vinogradova@unibas.ch
Institute for Biomedical Ethics, University of Basel, Switzerland

Advanced Directives (AD) were debated in the world media landscape long before the COVID-19 pandemic. In Switzerland, they were discussed not only in the medical context, but also at the governmental level: in 2018, members of parliament proposed to make Advanced Directives (AD) mandatory for everyone above 50 years. The COVID-19 epidemic made the AD issue relevant again, especially in the context of patient triage (hospital and pre-hospital) when resources in the healthcare system are scarce. Do States have the right to force citizens to sign AD, thereby pressuring them to think about the dying process? Despite the inevitability of death, is it morally right to force citizens to think about death at a certain stage in their life (e.g. at 50) or in certain circumstances (e.g. when healthcare resources are scarce)? Can ADs be used against citizens themselves when States are corrupt and abuse their monopoly on power? In this presentation, the author plans to compare experiences in the use of AD in different countries, especially among elderly patients. By raising this topic, the author aims to look at AD-issue from a new, political-philosophical perspective, and to offer different ways of using the AD in times of scarcity of resources in extreme circumstances.

"**If you hear it from a doctor, you internalize it."**
Medical Gaslighting in the field of rare diseases –
insights from a qualitative interview study

Sebastian Wäscher

sebastian.waescher@uzh.ch
Institute of Biomedical Ethics and History of Medicine, University of Zurich, Switzerland

Gaslighting originally describes a manipulative behaviour in individual relationships that leads to mental anguish of the victim due the constant questioning of the victim's perception of reality. Medical gaslighting adopts the concept to the healthcare sector and raises awareness to individual and structural situations in which patients experience dismissal and invalidation. The phenomenon has been observed especially in marginalized groups in the health care sector.

Interestingly, this concept has not yet been utilized in the field of rare disease. Although people suffering from a rare disease are usually marginalized and often suffer from mental health issues. Based on the preliminary results of a narrative interview study, I will introduce the concept of medical gaslighting to the field of rare diseases. Based on 34 interviews with a total duration of over 60 hours, I will exemplify individual experiences of medical gaslighting among patients with rare disease.

I will conclude the presentation with a theoretical analysis of how the concept of medical gaslighting can be a useful heuristic for drawing attention to deteriorating tendencies in patient-physician relationships.

95

A scoping review on involving patients and relatives in clinical ethics consultation

Manuel Trachsel

manuel.trachsel@usb.ch
University Hospital Basel, Switzerland

Background. Most approaches to clinical ethics consultation (CEC) aim to involve patients and relatives in its process. However, a consented categorization and operationalization of forms of involvement is lacking, which impedes research on the current extent of involvement as well as approaches for increasing it.

Methods. We conducted a scoping review of the literature on forms of involvement of patients and relatives in CEC.

Results. Sixty-four publications were identified, based on which eight forms of involvement were developed: (1) awareness of existence or function of CEC, (2) notification of a CEC, (3) opportunity to initiate or refuse a CEC, (4) engagement of patient's perspective in CEC, (5) participation, (6) representation, (7) access to documentation, (8) opportunity for feedback.

Conclusions. There is considerable variance in terms of categorization and operationalization of forms of involvement of patients and relatives in CEC. We propose an integrative framework as foundation for gathering comparative data on the extent of involvement across CEC services and countries, as well as the development of interventions for increasing it.

Futility and Palliative Approaches in Caring for Persons with Anorexia Nervosa

Manuel Trachsel

manuel.trachsel@usb.ch
University Hospital Basel, Switzerland

Background. The main moral conflict in anorexia nervosa has been located between applying coercion to prevent serious complications and accepting treatment refusals. However, empirical evidence on the ethical reasoning of health care professionals in these challenging situations is scarce.

Methods. I content analyzed all documentations of ethics consultations concerning anorexia nervosa from one Clinical Ethics Support Service in Switzerland (19 documentations with a total of 130 participants).

Results. In nearly all ethics consultations, concerns about futility were voiced. Discussed options included prioritizing harm reduction and/or relief of suffering (palliative intent) over weight normalization (curative intent). However, health professionals were uncertain whether palliative approaches could be justified. By comparing the (weighing of) arguments between cases in which, ultimately, a curative vs. palliative goal was chosen, I identified morally relevant differences such as subjectively acceptable vs. unacceptable quality of life and beneficial vs. harmful effect of previous coercive treatment.

Discussion. The dilemma of being obligated to treat in the face of probable futility may be resolved by shifting to palliative approaches to care. However, this is currently hindered by uncertainty around justifiability and eligibility. Based on my findings, I developed a framework for decision-making about goals of care in anorexia nervosa.

Ethics Mentors as a hub-and-spoke-model – development and experiences

Katharina Woellert

k.woellert@uke.de
University Medical Center Hamburg-Eppendorf, Germany

Ethical quality of care describes a state of affairs in which generally accepted ethical standards are considered in regular care. A prerequisite for this is an effective interaction between the healthcare professionals involved. Clinical ethics has a supporting function that requires effective integration into the organization. The larger an organization, the more difficult it is to spread the know-how of clinical ethics. At the University Medical Center Hamburg-Eppendorf (UKE), an „Ethics Mentors" program has been in place since 2020 that answers this challenge. It was developed specifically for the needs of the UKE and bases on the hub-and-spoke model. The starting point was the observation that many staff members at the UKE were trained in clinical ethics and not only contributed their competencies to ethical case consultations but, above all, to regular communication in their respective areas of work. However, they needed more conceptual integration into the overall organization. Various stakeholders were involved in developing the program, especially the trained UKE-members. I will present the program, its development, theoretical background, and experiences in its implementation.